Debating Stem Cell Research and Human Cloning: Multiple Meanings, Competing Constructions

Sarah Parry

Ph.D
University of Edinburgh
2003

For Nick

I declare that this thesis is my own work throughout.

Sarah Parry
Science Studies Unit, Sociology
University of Edinburgh
1st October 2003

CONTENTS

Acknowledgements

I am greatly indebted to all the people who generously gave their time and valuable contributions to this thesis by participating in focus groups or interviews. In addition to this, there were numerous people who worked 'backstage' in providing useful contacts, setting up the focus groups, and offering their own insights into the issues around stem cell research and cloning. Without the help and cooperation of all of these people, this thesis would not have been possible.

Within the immediate family of the SSU, I would like to thank all the people who have helped me over the last four years in numerous ways that have extended beyond the call-of-duty of 'office-mate', 'colleague' and, of course, 'secretary'. These categories do not really fit with my experiences of our relationships, especially as developed over tea, cake and alcohol! Beyond the SSU, there has been a great deal of support from those in Sociology, not least for providing me with a regular drinking event and paid employment for the foreseeable future.

I would also like to say a huge thank you to my supervisors – Sarah Cunningham-Burley and Wendy Faulkner – for their ongoing support and advice in numerous ways, and for leaving me to get on with it for the most part!

No thesis acknowledgements would be complete without mentioning Mum and Dad, whose love and support have greased the wheels of life in countless ways. Thank you. Finally, a very special mention goes to my "Charming Man" and, more importantly, my best friend Nick, to whom this thesis is dedicated.

ABSTRACT

The stem cell research (SCR) and human cloning debates are a site where we can explore the multiple and competing constructions associated with new and controversial technological innovations. The aim of this thesis is to explore the multiple and competing discursive constructions of these developments, tracing how dominant definitions have emerged and others marginalised or silenced. By analysing the public debates I am able to explore the negotiation of discursive boundaries during current processes of entrenchment. In order to access a range of meanings, the thesis draws on four sites of qualitative data collection: 1) the UK parliamentary debates that led to the amendment to the Human Fertilisation and Embryology Act (1990) to permit embryonic SCR, 2) interviews and focus groups with couples in IVF programmes who are potential embryo donors for SCR, 3) interviews and focus groups with patient support groups on whose lives SCR may have an impact, 4) interviews with scientists working in the field of SCR and cloning-related developments.

The starting point for my research is a discursive analysis of the UK Parliamentary debates on cloning and SCR where I examine the rhetorical strategies of and manoeuvrings over the meanings of stem cells, cloning and embryos. Here I draw parallels with the rhetorical devices and legislative outcomes of the embryo debates from the 1980s, such as the return to the 'embryo question' and the construction of health and illness. Following on from this the thesis explores the perspectives of scientists, patient group members and those enrolled in IVF programmes, in order to access their views within their own terms of reference. This part of my thesis examines the uses of cultural tropes and idioms, such as the cultural framing of risk, and constructions of science, public(s) and expertise. Shaped by the disciplinary and methodological foundations of cultural studies, sociology and science and technology studies, I have focus upon how constructions of SCR and human cloning-related developments are embedded in wider social norms and values.

Central to my analysis is the mobilisation, negotiation and reconstruction of binary classificatory systems by a range of actors within the debates. Categories, such as nature/culture, health/illness, expert/lay, science/society, serve as powerful, yet flexible, rhetorical tools through which meanings around SCR and cloning are negotiated. In the context of science-public relations in the SCR and cloning debates, my research elaborates on how demarcations between expert/lay, objectivity/subjectivity etc. are flexibly rendered in ways that preserve the hegemonic position of science and scientists, thus marginalising alternative accounts. At the same time, however, I illustrate that some scientists are presenting more reflexive accounts of their work, pointing to a shift in expert/lay relations. In adopting an eclectic theoretical framework, my thesis contributes to contemporary sociological debates including critical approaches to the public understanding of science, sociocultural constructions of risk and the (re)constitution of classificatory systems.

By identifying 'experts" rhetorical manoeuvrings and devices alongside that of the 'public', this research offers a valuable contribution to debates on science-public relations – one which facilitates a more inclusive discussion of the current and future implications of SCR and cloning-related developments as well as policy decision-making processes.

CHAPTER I

Introduction

1.1 Aims and Rationale for Thesis

In 1997 a team of researchers from the Roslin Institute, Scotland, announced that they had produced Dolly the sheep – the first mammal to be cloned from an adult cell. Just over one year later, in November 1998, two teams of researchers in the US announced that they had isolated and cultured the first stem cell lines. These seemingly unrelated scientific breakthroughs have generated a complex set of debates within the UK (and elsewhere) that I refer to as, the stem cell research (SCR) and cloning debates. The birth of Dolly demonstrates the ability to clone mammals, potentially including humans, from cells taken from an adult of the same species – a procedure previously regarded as 'biologically impossible' (Wilmut *et al.*, 2000: 17). The second development – the isolation of stem cell lines – marks the ability to grow cells, taken from human embryos, indefinitely, in the laboratory and to cultivate them into specific cell types – nerves, cartilage, bone, muscle and guts (see Radford, 1998a, 1998b, 1998c). These cells could then be used for medical treatments and transplanted into patients.

The symbolic, ethical, legal and scientific potency of these developments emerges in their potential convergence, when the cloning technique is used to create cloned stem cells used for transplantation (see Appendix II). Although human reproductive cloning is subject to prohibitive legislation in the UK, SCR, the creation of cloned embryos and 'therapeutic' cloning are all permitted. Such practices require a combination of various techniques and knowledges, including the nuclear transfer technique, cell differentiation (see Appendix II), and the material product of IVF treatments – 'healthy' human embryos. In this respect, as Glasner has argued in the context of what has been called the 'new genetics', developments in SCR and cloning embody a new set of sociotechnical relations involving new groups of actors, 'including funding bodies, government and regulatory agencies and firms as well as scientists' (2002: 272). Subsequently, this area has become a social, legal, ethical and regulatory quagmire, with competing positions around what SCR and cloning is and how it should (or should not) proceed (see, for example, Holland *et al.*, 2001; Kolata, 1997; Nisbet *et al.*, 2003; Nussbaum and Sunstein, 1999).

Debates surrounding SCR and cloning are being conducted at a time when the research remains experimental and clinical applications are theoretical. Despite this, or perhaps because of this, the issues generated by SCR and cloning-related developments are waged at the level of deeply held sociocultural assumptions. Like other areas of the new human genetics, I have been struck by what Sarah Franklin calls the '*simultaneous enormity and intimacy*' (2001c: 336, original emphasis) of SCR and cloning. Few seem to doubt the potential of this area to transform medicine or our understanding of the human body, health and illness. But beyond this, SCR and cloning touch upon and threaten to transform fundamental aspects of what it means to be human, such as human uniqueness, as well as wider issues surrounding the limits of science and technology, the relationship between science and commerce, and constructions of expertise and scientific progress (see Franklin, 2001c; Petersen, 2002; Williams *et al.*, 2003).

When I embarked upon this doctoral research in 1999, there was a lack of in-depth social science research exploring what is at stake in these debates or how SCR and cloning are being constructed as scientific and social practices for different social groups. In the UK, the SCR and cloning debates tended to be confined to policy and legislative discussions (see Chapter 3), as media spectacle (see Nerlich and Clarke, 2003; Petersen, 2002; Williams, 2003), or were subject to abstract ethical and philosophical theorising (see Harris, 1998; McGee, 1998, Nussbaum and Sunstein, 1999), and cultural commentary (see Appelyard, 1999; Kolata, 1997). The only available study, titled *Public Perspectives on Human Cloning* (1998), was commissioned by the *Wellcome Trust* and investigated the perspectives of non-scientists on human cloning. Using focus groups, the researchers conducted group interviews before and after participants attended an 'educational' session to learn about the scientific and technical practices involved in cloning. They found that the public articulated the same concerns about SCR and cloning in both sessions, but in the second utilised the 'scientific' knowledge gained during the 'educational' session in order to reinforce their arguments. The *Wellcome Trust* report demonstrated that 'publics" were highly sceptical of modern science and scientists, and equally distrustful of government and related policymakers. Participants also felt that their views were undervalued in policy and other decision-making contexts.

In 1999 Sarah Franklin wrote a review essay, *What We Know and What We Don't About Cloning and Society*, where she began to probe existing contributions to the cloning debates. The crux of the problem, according to Franklin, is that existing contributions to the cloning debates misplace the 'problem'. As she argues, 'the real challenge is not what to do about it, how to regulate it, whether to permit it or not, but how more democratically to conduct a less exclusive conversation' (1999d). This 'challenge' is a central feature of my research. In order to get behind

the SCR and cloning debates as media spectacle or regulatory dilemma, this PhD aims to examine what meanings both scientists and non-scientists attach to SCR and cloning-related developments. This requires mapping out the range of actors and voices for whom such developments may have an impact, in order to then access the multiple discourses mobilised for constructing meanings around SCR and cloning. To explore how this area is being discursively constructed, I selected a range of data collection sites that can be listed as follows:

i) Discursive analysis of UK (Westminster) Parliamentary debates;
ii) Two focus groups with infertility support groups;
iii) Four focus groups with patient support groups: Huntington's Disease Society, Diabetes UK, Cardiac Support Group and Alzheimer Scotland: Action on Dementia;
iv) Four interviews with scientists working in the area of SCR and/or cloning-related developments (three one-to-one interviews and one with two scientists); and
v) Thematic collection and analysis of media texts.

These sites have been chosen because they allow me to access both dominant and marginalised discourses. The choices made are further discussed in the following section where I elucidate on my research questions and objectives.

1.2 Research Objectives and Questions

This doctoral research has three interrelated objectives:

1.2.1 To identify both dominant and marginalised discourses surrounding SCR and cloning. Thus, I sought:

- To identify key public sites where the SCR and cloning debates are taking place.
- To identify dominant constructions of SCR and cloning and the key institutions and/or individuals contributing to such meanings.
- To identify groups and/or individuals that have been marginalised within the dominant SCR and cloning debates.
- To identify marginalised discourses surrounding SCR and cloning.

Shaped by the disciplinary and methodological foundations of cultural studies, sociology and science and technology studies (STS), this thesis maps a range of dominant and marginalised

discourses surrounding SCR and cloning-related developments. Epistemological assumptions associated with these approaches have played an important role in influencing the research design, for example in the concern with dominant and alternative meanings and perceptions. In order to get beyond SCR and cloning-related developments as media spectacle, I felt it was important to explore both dominant and alternative discourses alongside one another, and identify corresponding individuals and groups.

Firstly, I have identified dominant meanings, or what Stuart Hall calls 'preferred' meanings (1980), of SCR and cloning-related developments within public debates. Secondly, I have been concerned with alternative or marginalised discourses that are potential sites of resistance to those dominant positions. Thirdly, in exploring both dominant and alternative constructions I revealed the flexibility of discourses (both dominant and alternative), thus demonstrating how the production and interpretation of meanings and 'knowledge' of cloning-related developments are intimately linked to their social context (see Cunningham-Burley and Kerr, 1999).

In keeping with cultural studies approaches that have emerged since the 1980s, public debates on SCR and cloning are viewed as sites of struggle over meanings, with different groups vying for power and authority over definitions (Schulman, 1993). According to such a position, it is important to include a range of individuals and groups within the research who inhabit different social and cultural positions vis-à-vis technoscientific developments of SCR and cloning. Following the research of Pinch and Bijker (1984), the starting assumption is that different people, or 'relevant social groups', make sense of technoscientific developments in different ways.[1] By attending to the views of actors who have gained ascendancy within the public debates on SCR and cloning as well as marginalised groups with a stake in such developments, I sought to investigate 'flexibility in how people think of, or interpret, artefacts' (Pinch and Bijker, 1984: 421).

Politically, the thesis takes inspiration from the writings of scholars in the areas of cultural studies of science and technology (e.g. Cussins, 1998a, McNeil and Franklin, 1991) and critical approaches to the public understanding of science (cPUS) (see chapter 4). Whilst there has been a tendency within the field of STS (feminist or otherwise) to either focus upon 'what scientists think and do' (Reinel, 1999: 163) or to emphasise agency and resistance of subordinate groups

[1] 'Relevant social groups' are groups who share a set of meanings in relation to the specific artefact, such as patient groups, 'mothers' or scientists working on SCR (Pinch and Bijker, 1984: 414). However, as I will show throughout this thesis, there is often considerable variability within what appears to be a relevant social group. Therefore, this concept is used as a methodological rather than an analytical tool.

and popular culture (see McNeil and Franklin 1991, Reinel, 1999), the work of people such as Franklin (1997), Michael (1996a), Kerr *et al.* (1997; 1998a; 1998b) and Cunningham-Burley and Kerr (1997) have been instructive in bringing the two together. Synthesising an analysis of both scientists' and publics' accounts of SCR and cloning is consistent with the STS understanding of the mutual constitution of science, technology and society.

There are a number of features to this approach. By paying attention to both dominant and marginalised sites within the SCR and cloning debates, my concern is not to 'reject science and technology but try to negotiate a critical politics' about them (Cussins, 1998a: 168). In keeping with the long-standing endeavour of the sociology of science and technology and more recently, the sub-field of cPUS, I seek to challenge the privileged epistemological status of science and scientists as *the only* legitimate producers of knowledge.

1.2.2 To examine meanings and perspectives of SCR and cloning and how they are constructed by relevant social groups and individuals within them

- How do 'dominant' and 'marginalised' groups construct SCR and cloning.
- How are meanings and perspectives constructed within relevant social groups?
- What cultural resources and discursive repertoires are mobilised?
- What wider social and cultural values are reflected in constructions of SCR and cloning?
- How are people's views of SCR and cloning shaped by their lived and embodied experiences?

The thesis is concerned with how constructions of SCR and cloning-related developments are embedded in wider social norms and values, and, hence, are inseparable from 'everyday life' (McNeil and Franklin, 1991: 133). My analysis of the SCR and cloning debates is sensitised to the range of discursive repertoires, cultural resources and rhetorical strategies mobilised by actors when making sense of these new developments. In particular, I illustrate how people's accounts of this area of research are shaped by their lived and embodied experiences, for example, by their profession, gender, health status, as a family member or as a citizen. At the same time, however, I seek to illustrate that people's views of SCR and cloning cannot be 'explained away' through one aspect of their identity (e.g. their health or professional status) but are constituted in complex and contradictory ways.

Rather than understanding scientists as simply engaging in objective, 'pure', knowledge-seeking research practices, I start with the assumption that scientists produce situated knowledge (see Haraway, 1991) that is reflective of both professional *and* wider social and cultural values. To this extent, science is inherently social and value-based. Similarly, 'public' groups draw upon a range of 'knowledges' including experiential and culturally-based knowledge along with 'expert' accounts that they have encountered through the media, education, contact with GPs, colleagues and friends. It is, therefore, important to explore the significance of these accounts for different groups and individuals, investigating *how* these are mobilised when constituting their views on SCR and cloning-related developments.

For these reasons, the accounts of politicians, scientists and other relevant social groups are treated as both a topic *and* a resource. That is, they are understood as reflecting particular versions of SCR and cloning and yet are treated as partial, contingent and subject to change. Meanings are never 'won' but are always negotiated and always subject to competing versions, experiences and 'knowledges'.[2] As a result, the researcher must sensitise oneself to the range of meanings and perspectives within the SCR and cloning debates, and seek to move beyond the dominant rhetoric that emerges within the media and policy documents.

1.2.3 To explore particular themes within these discourses.

- How do different groups and individuals manage risk and uncertainty?
- To what extent are accounts of SCR and cloning characterised by contradictions and ambivalence about science and technology?
- How are boundaries between science/society, expert/lay, scientists/publics (re)constructed and mobilised?
- How is 'nature' constructed in the SCR and cloning debates, and to what extent are classificatory systems around 'nature' destabilised by these developments?

This third and final research objective seeks to identify recurrent themes across the data collection sites. In exploring people's accounts of SCR and cloning, it is important to investigate themes that seem to crosscut various accounts and to analyse how these are mobilised and negotiated. When collecting and analysing my data, I sensitised myself to how boundaries

[2] I also acknowledge that some sociotechnical artefacts and practices are more stable than others. Stabilization, however, is achieved by a range of sociotechnical processes that marginalises competing interpretations in order for a dominant set of meanings to emerge (see, for example, Hall, 1980; Pinch and Bijker, 1984; Michael, 2000).

around categories such as 'science', 'expertise', 'publics', and 'nature' are constituted, negotiated and blurred. These categories are understood to be flexible and socially constituted vis-à-vis SCR and cloning-related developments, rather than being *a priori* categories through which knowledge about ourselves and our world is constructed. Developments in SCR and cloning were taken as troubling conventional understandings of such categories, providing an analytical window for exploring how classificatory systems are dynamically (re)negotiated. A further overarching theme is that of ambivalence and contradictions. Here I aim to move beyond polarised accounts of SCR and cloning that seek to understand accounts as either for or against, as hopeful or fearful and to show how such positions co-exist in people's accounts of this area.

Of course, the themes highlighted are not plucked out of the air, but are indebted to a range of related studies conducted within sociology, cultural studies and STS. For instance, the research conducted by Sarah Cunningham-Burley, Anne Kerr and Amanda Amos (see, Cunningham-Burley and Kerr, 1999; Kerr *et al.*, 1997, 1998a, 1998b; Kerr and Cunningham-Burley, 1999) has emphasised how boundaries between science/society and experts/publics are flexibly deployed in scientists' accounts of the new human genetics. In the same set of studies, they have shown how both scientists' and 'publics' ' accounts of the new genetics are characterised by ambivalence and contradictions. The work of Cunningham-Burley *et al.* closely corresponds to a range of related studies within the field of sociology and STS such as Michael (1996a), Irwin and Wynne (1996a) and Irwin (1995), which have focussed upon and problematised science-public relations in various research contexts.[3]

1.3 Wider Relevance

My analysis of the SCR and cloning debates builds upon existing research within the sub-field of critical approaches to the public understanding of science (cPUS). Following on from the work of people such as Franklin (1993, 1997, 1998, 1999, 2001a, 2001b, 2001c) Irwin and Wynne (1996a), Kerr *et al.* (1997, 1998a, 1998b), Michael (1996a, 1996b, 1998) and Wynne (1988, 1992, 1995, 1996, 2002), this thesis problematises and opens up our understanding of taken-for-granted categories. I investigate how particular versions of SCR and cloning are conferred with authority and legitimacy while others are marginalised or silenced. In analysing both dominant and marginalised accounts of SCR and cloning, I tie my analysis to issues of power. For instance, I explore some of the discursive and institutional mechanisms involved in privileging some accounts as 'valid knowledge', and how particular models of science-public relations excludes the voices of some public groups. Here, I show the significance of doing boundary

[3] For further discussion of these approaches, see Chapter 4.

work around what counts as 'science', 'expertise' or 'nature' and yet how developments in this field trouble such categories. Such an analysis illustrates how boundaries between categories are flexible rather than fixed, multiple rather than singular.

In the broader context of a 'crisis of legitimacy' – as it is often referred to by spokespeople for institutions such as the Royal Society (see Franklin, 2001c) – my analysis of the SCR and cloning debates contributes to work that critically appraises attempts by governments and industry to counter public anxieties. Firstly, this thesis highlights that such a crisis is overblown or, perhaps, misdirected. Whilst people are sceptical towards science and anxious of developments in SCR and cloning, this is coupled with trust and expectation. It seems that despite the apparent shift towards reflexivity in scientists' discourses and policymaking practices, 'public' understanding of science continues to be, at best, misunderstood and at worst, silenced. The complexities of people's views towards developments such as SCR and cloning continue to fall outwith today's models of science-public relations and policymaking practices, and thereby cry out for more inclusive approaches to debating controversial developments in science, technology and medicine.

The findings of this thesis also contribute to debates within sociology, cultural studies and STS on how sociocultural categories are constructed and negotiated in particular contexts. For example, social scientists have commented on the current transformations taking place in society and the implications of these for constructions of expertise and expert/lay relations (see, for example, Beck, 1992; Irwin, 1995). In the SCR and cloning debates, I show how the contingencies of categories such as 'expertise', 'nature' and 'human' are rendered explicit. To this extent, these debates offer new openings for rethinking such categories. Furthermore, boundaries between binary categories, such as expert/lay, science/society, human/non-human, nature/culture, are increasingly blurred. For these reasons, it is necessary for social scientists to continue to develop appropriate and imaginative methodological, analytical and theoretical tools for capturing such transformations.

1.4 Outline of Thesis

Because the topic calls for an appreciation of the range of issues generated, this thesis is ordered thematically. Each chapter draws on a distinct set of theoretical and conceptual tools and yet is underpinned by the broad approach outlined above. For this reason, the reader will not find an overall literature review of the field to orient the thesis as a whole but will be introduced to relevant theories and concepts as the thesis develops.

The first of the 'data chapters', Chapter 3, is a discursive analysis of the UK Parliamentary debates on SCR and cloning that led to a change in the law to permit embryonic SCR (eSCR) and the creation of cloned embryos for research and 'therapeutic' uses. This chapter provides an overall introduction to many of the pertinent issues in the SCR and cloning debates that will be revisited at various points throughout the thesis. Framed around five subheadings, Chapter 3 illustrates the discursive strategies and repertoires mobilised for constructing what has become the dominant account SCR and cloning in the UK. The meanings of stem cells, cloning and embryos are shown to be plural and contested, with some accounts gaining ascendancy whilst others fall by the wayside. In drawing direct parallels with the embryo debates of the 1980's, I show how the 2000/2001 debates involve a 'return to the embryo question'. This feeds into an analysis of the ways in which two specific groups are discursively invoked and constructed – those with diseases and disabilities who have been identified as likely to benefit from stem cell therapies, and couples undergoing fertility treatment who are needed to donate 'spare' embryos.

Chapter 4 provides a theoretical and conceptual orientation for chapters 5, 6 and 7. In this chapter I consider the nature of and extent to which science-public relations are undergoing transformations in contemporary society. Building on my analysis of Parliamentary transcripts, I argue that there are a number of core issues at stake in the SCR and cloning debates illuminated by the approaches of Beck and literature from the critical public understanding of science (cPUS). Specifically, I consider how Beck's 'Risk Society' thesis (1992) and cPUS approaches have contributed to analyses of expertise, risk, trust, and uncertainty, and discuss a number of studies that have examined how scientists and related institutions have responded to public anxieties towards science (e.g., Brown and Michael, 2002; Irwin, 1995; Irwin and Wynne, 1996a; Wynne, 1996). One of the main claims here is that apparent shifts towards reflexivity within the accounts of scientists and spokespeople for institutions such as the Royal Society, sit alongside attempts to shore up scientific authority and legitimacy. This tension, I argue, is a central feature of science-public relations today and forms a backdrop to the SCR and cloning debates.

Chapter 4 underpins my analysis of scientists' and publics' accounts of SCR and cloning, as presented in Chapters 5, 6 and 7. In adopting a theoretical and analytical framework that comes from synthesising Beck and cPUS, I go on to investigate how SCR and cloning is constituted by different actors. The remaining chapters examine the range of discursive strategies mobilised by participants in interviews and focus groups and highlights how people's views are shaped by embodied and lived experiences.

Chapter 5 focuses on the accounts of five scientists working within the field of embryonic SCR, who I refer to as 'core-eSCR-scientists'. Based upon data collected during interviews with these scientists, I explore the range of discursive strategies and repertoires mobilised by scientists in order to manage and resolve elements of this controversy. Here, I highlight how in constituting a particular 'version' of SCR and cloning, core-eSCR-scientists constitute themselves as particular sorts of actors, whilst simultaneously constructing others around them. My analysis reveals how scientists appeal to and yet blur boundaries between science/society, expert/non-expert, certainty/uncertainty, and inside/outside in order to construct their work as legitimate and reassert themselves as 'experts'. This involves enrolling some public groups – specifically patient groups – while continuing to exclude others. The legitimacy of eSCR is further achieved by excluding scientists who claim to be involved in reproductive cloning from the bone fide scientific community. Chapter 5, therefore, directly builds upon Chapter 3 to the extent that it is an analysis of actors whose voices have been present, and indeed dominant, within the public SCR and cloning debates in the UK.

In Chapters 6 and 7, I turn my attention to the accounts of members in five patient support groups – Diabetes, Huntington's, Cardiac and Alzheimer's – and two infertility support groups. These chapters show how people who have been invoked in the dominant debates and discourses on SCR and cloning make sense of this area of research according to their own terms of reference. Analysis of people's accounts illustrates the rich discussions generated within focus groups and interviews. Additionally, participants' views of this area of research are revealed to be characterised by ambivalence. In keeping with the cPUS approach outlined in Chapter 4, Chapters 6 and 7 attend to the discourses and views of SCR that have been marginalised in the dominant public debates. When compared to the accounts of patient support groups within the Parliamentary debates and the accounts of core-eSCR-scientists (in Chapter 5), my analysis in Chapters 6 and 7 shows that 'publics" views have been marginalised and excluded. It also challenges the presumption made by core-eSCR-scientists and politicians within the Parliamentary debates, that people who may benefit from stem cell therapies are wholly and uncritically in support of developments in this area.

Chapter 6 shows how, in contrast to the scientists' accounts discussed in Chapter 5, the publics' views of SCR and cloning 'open up' the debates, offering alternative ways for framing the issues and identifying problematic aspects of these developments. What this chapter reveals is the tension between a pervading sense of uncertainty and more optimistic belief in the potential of science, technology and medicine to develop new treatments or cures. People's views are shown to be complex, ambivalent, and shaped by their experiences and social situatedness (as the work

of Wynne and others in cPUS also indicates). This chapter is framed around four themes: discussions around the 'slippery slope' from 'therapeutic' to 'reproductive' cloning, the (in)efficacy of regulation and control of science, how participants reflected upon science-public relations, and how patients mobilise experience-based expertise. All of the themes are significant gaining a deeper understanding of science-public relations because they reveal how expertise is constructed, challenged or affirmed by non-scientists.

Keeping risk, expertise and trust as crosscutting themes, Chapter 7 compares the views of people in fertility and patient support groups on embryos and embryo research. This chapter builds upon existing feminist analyses of new reproductive technologies and embryo research (e.g., Cussins, 1998a, 1998b, 1998c; Franklin, 1997; Goslinga-Roy, 2000; Morgan and Michaels, 1999; Spallone, 1989), and explores the contingent meanings attached to embryos in the current context of the SCR and cloning debates. In particular, I highlight how people's views of embryos and the use of embryos for SCR are shaped by a range of embodied and experiential 'knowledges'. For those undergoing fertility treatment, I show that the 'viability' of embryos is an important issue when considering their position on eSCR. To use embryos that are graded as 'viable' for anything other than reproductive purposes, generated a great deal of concern and anxiety. Contrastingly, one of the key concerns for people within patient support groups relates to distinguishing embryos from foetuses or children. Here the process of distinguishing 'early embryos' from 'foetuses', and aligning the former with biological material and the latter with 'life', is rendered visible within the patient group discussions. I also argue that, within the patient support groups, the classification of embryos as 'spare' or 'waste' is a central and powerful discourse that influenced people's views of eSCR. Finally, shifting focus to the policy implications of my analysis, I argue that the dominant rhetoric of embryos within the Parliamentary debates and scientists' discourses takes for granted the willingness of 'couples' to donate their embryos for SCR and exaggerates the 'demand' for stem cell therapies from people with conditions such as Diabetes.

The final chapter, Chapter 8, focuses on the dynamics involved in negotiating and classifying SCR and cloning as 'natural' or otherwise. I show how distinctions between binary opposites, such as nature/culture, are central to processes of meaning-making and yet these are managed in flexible ways by those who participated in focus groups and interviews. Chapter 8 illustrates how SCR and cloning unsettles 'naturalised' understandings of kinship, human uniqueness, reproduction and the human life course, thus revealing the social constructedness of 'nature' to me, as the analyst, as well as those who participated in discussions. Analysis of people's accounts of SCR and cloning exemplify how categories of 'nature' are mobilised, contested and

reconstructed; 'nature' is never fixed, but shifting, contested, renegotiated. My analysis of people's accounts of SCR and cloning, confirms arguments that categories of 'nature' are achieved through processes of naturalisation, denaturalisation and renaturalisation (Franklin et al., 2000: 19). It also raises the veracity of Kristeva's concept of 'abjection' (1982) as a useful tool that captures moments within that process when novel practices are yet to be categorised.

The thesis concludes by pulling together some of the threads that cut through my analysis, considering the practical and policy implications of my research, and the its relevance to the social sciences. Here, I situate my work within the cPUS approach, offering some thoughts on the direct implications for the SCR and cloning debates as well as for wider issues surrounding the new genetics. Finally, I revisit how my research has contributed to concepts such as trust, risk and boundary work, and develops a more sophisticated understanding of how binary categories are (re)constructed in the SCR and cloning debates.

CHAPTER II

Research Design and Methodology

2.1 Introduction

This thesis is an exploration of people's views of SCR and cloning, looking at accounts that have gained ascendancy alongside those that are marginalised. It is both an analysis of dominant sites and related discourses, as well as showing how we can move beyond these to create a more inclusive and open debate. Informed by the disciplinary and methodological foundations of sociology, cultural studies and STS, I attend to three research objectives: to identify both dominant and marginalised discourses surrounding SCR and cloning, to examine meanings and perspectives of SCR and cloning and how they are constructed by relevant social groups, and to explore particular themes within these discourses. The thesis aims to contribute to policy debates and those within the academy.

This chapter provides an account of the research design as a process and practice. Starting with an overview of the choices made during the early stages of developing this thesis into a 'workable' project, I chart the evolving nature of the research design. I go on to describe data collection practices adopted, reflecting on the methods chosen and how I came to identify relevant social groups. Then I turn my attention to the various elements of the data collection and analysis process. Here I attend to issues such as gaining access, developing an appropriate topic guide along with particular experiences and insights gained when conducting focus groups and interviews. Two specific problems that I encountered are discussed in detail – the presence of authority and a failed interview – in order to elaborate on the contingencies of successful qualitative data collection procedures. Finally, I reflect on the research process and limitations of the study.

2.2 Research Design

2.2.1 Evolving Research Design

In order to access the ways in which people construct meanings around SCR and cloning, I adopted a flexible qualitative research design, similar to that of 'grounded theory' (see Pidgeon,

1996). The research design was not intended to reach a point where there emerged a fixed methodological protocol to follow. Instead, it evolved through conducting background research of existing social science literature, surveying the technoscientific developments, media texts and public reports in order to develop a map of the UK debates. Whilst the research was informed by various theoretical positions and existing literature on related areas, I did not want to impute theoretical categories onto the data. Instead, I placed a greater emphasis on allowing research categories to be generated by the data obtained. This iterative method requires a flexible research design, enabling the research process to be guided by the ongoing and dynamic process of data collection and analysis.

2.2.2 Selecting Written Sources and 'Relevant Social Groups'

With the above in mind, one of the central questions relates to what constitutes a relevant social group and how, as a sociologist, one could identify 'dominant' and marginalised relevant social groups? This question has been similarly pondered by Mike Michael who asks whether relevant social groups is 'an actor's category, or an analyst's?' (2000: 6). In a case such as SCR and cloning, this question becomes even more problematic when one considers the potential implications of these developments across a number of sociocultural spheres including healthcare, medical regulation and science-public relations, as well as for categories such as health, illness, life, nature and culture. Thus, if we start with the assumption that SCR and cloning-related developments have the potential to affect the lives of all members of our society, then all members of our society are potential 'relevant social groups' (and participants in this research).

Conducting data collection and analysis for a PhD project such as this, involves explicit choices regarding who and what to include for practical purposes. A preliminary content analysis of policy documents, parliamentary SCR and cloning debates, and media commentary was conducted in order to outline the relevant sociological issues and to reveal the ideological dimensions underpinning SCR and human cloning discourses and practices. This was a particularly useful means for addressing the multiple and often contradictory ways in which SCR and cloning is being constituted by various groups and individuals. By conducting a 'data driven' analysis (see Tonkiss, 1998: 250), I began to identify emerging themes to both narrow the research focus and map the range of key actors and organisations within the public debates.

Combining the preliminary analysis of the parliamentary debates and media texts was vital in ascertaining who the key actors and institutions are. From here, I identified relevant social

groups within and outwith science who were involved and/or invoked in the parliamentary debates and media texts during the period of 1999-2000. These groups were scientists working in the area of SCR and cloning-related developments, people undergoing fertility treatment who are required to donate embryos for the research to continue, and numerous patient groups on whose lives these developments may have an impact (for example, people with Huntington's Disease and Diabetes). I then drew up a list of potential individuals and groups within the Edinburgh area to be included in the research.

By adopting the categories used in Parliament, I could be criticised for merely reproducing the categories imposed upon those groups. However, my methodological and analytical approach is critical of the 'dominant' debates and aims to redress the gaps, giving voice to groups who were invoked but not included in the debates. For instance, although patient groups had been included in the parliamentary debates, this had occurred by proxy (e.g. within politicians accounts or represented by patient organisations) and their views had not been directly accessed. Similarly, people undergoing fertility treatment were largely omitted from the dominant debates. Directly accessing the views of key scientists was thought to be important to get beyond the journalistic style of questions and answers reflected in newspaper articles, in order to explore the ways in which they construct their views on SCR and cloning. Additionally, less prominent scientists were included, as it was assumed that they might have less 'managed views on cloning – that is are yet to be groomed for media or public appearances. Whilst there were numerous other key actors that could have been included such as anti-abortion groups and representatives from national patient group organisations, I felt that the inclusion of patient groups identified fitted with the broader aims and objectives of the research.

2.2.3 Why Focus Groups?

Based upon the above observations, I could not assume that all potential participants had thought about or developed fully-formed views on human cloning. Hence, the use of focus groups was deemed to be appropriate for research with people who do not feel as though they have anything to say on the subject, or are reluctant to participate in a one-to-one interview (Kitzinger, 1996: 68).[1] The method, therefore, was intended as a means for allowing participants to 'generate their own questions, frames and concepts and to pursue their own priorities' according to their own terms of reference' (Kitzinger and Barbour, 1999: 5). By this connection, participants could engage in aspects of the discussion as and when they felt it appropriate, and 'opt-out' at points when they felt they had nothing to contribute.

[1] The latter point was felt to be specifically appropriate for those who were not scientists.

Pre-existing groups, as opposed to bringing together groups of strangers, were targeted because I felt that the patient support group or professional peer group (such as scientists who work together in a lab) would be one of the contexts in which ideas about SCR and cloning may be discussed and formed (Kitzinger and Barbour, 1999: 9). It was assumed that the familiarity of the group context would enable me to explore the everyday uses of language and communication used in interaction, such as teasing and arguing (Kitzinger, 1996: 68), along with the use of cultural resources such as jokes, references to fiction, TV and so on. As Kitzinger states, 'everyday forms of communication may tell us as much, if not more, about what people know or experience' (1996: 68). To look only at dominant discourses of associated with SCR and cloning, such as science articles, overlooks the variability and complexities of scientists' and relevant social groups' accounts. Focus group discussions, then, are ideal data collection sites where the researcher can sensitise oneself to the social situatedness of meanings that emerge and develop a sophisticated understanding of the intrinsic relationship between technoscientific practices and the wider social milieu.

2.3 Elements of the Data Collection and Analysis Process

Qualitative data collection processes are often a 'messy', non-linear, and ad-hoc experience. When conducting my research, I utilised a number of qualitative methods at a number of different sites which overlapped in time. These data collection sites can be presented as five distinct areas:

1. Discursive analysis of UK (Westminster) Parliamentary debates;
2. Two focus groups with infertility support groups;
3. Four focus groups with patient support groups: Huntington's Disease Society, Diabetes UK, Cardiac Support Group and Alzheimer Scotland: Action on Dementia;
4. Four interviews with scientists working in the area of SCR and/or cloning-related developments (three one-to-one interviews and one with two scientists); and
5. Thematic collection and analysis of media texts.

Whilst this list indicates the data collection sites that are analysed and discussed within the thesis, this does not reflect the entire range of people spoken to and material that I have consulted during the research process. The research design that evolved over a period of a year or so involved conducting some informal interviews to provide background information and to

get a 'feel' for the area. I have also spoken to an academic working in the area of genetics, a prominent science communicator in Scotland, a former infertility support group organiser, a medical ethics lawyer, and conducted a pilot focus group with undergraduate students from Edinburgh University. Other informal conversations with delegates at various relevant conferences provided rich background information which has fed into the research process in an iterative way. These conversations have pointed to relevant issues for consideration, for discussing the legal and scientific practices around SCR and cloning-related developments, providing contacts for interviews, and, therefore, had a profound effect upon the final design of this research.

In the following section I will discuss the data collection process which are separated into key sections: collecting written data for discourse analysis, issues of access, and conducting focus groups and interviews. The latter section is further broken down into developing a topic guide, group size, composition and setting; engaging in a dialogue; using pre-existing groups compared to one-to-one interviews; and finally a discussion of two problematic interviews.[2]

2.3.1 Collecting Written Data for Discourse Analysis

Access to the stem cell and cloning debates in Parliament was obtained through the Westminster website. All transcripts of debates are available in full, free of charge, and were printed out. In total, approximately fifteen hours of debates were analysed: two from the House of Commons (17 November and 19 December 2000) and one from the House of Lords (22 January 2001). Whilst issues around stem cell research and cloning were raised briefly in other parliamentary discussions, only discussions that took place during the time allocated to the 'stem cell debates' were formally analysed.

The use of discourse analysis for media texts was conducted in a less systematic manner. Keyword searches for clone, clones and cloning, were conducted in a number of different websites, including the *Guardian*, *BBC*, *Daily Telegraph*, *Independent* and the *Observer*. Science related websites were also searched: *New Scientist*, *Science*, and the *British Medical Journal*, along with the websites for relevant science institutions. While searching these sites, I also followed links to related sites and articles on cloning, such as commentary pieces and transcripts of television documentaries. All articles were then printed and catalogued.

[2] Throughout this chapter, 'interviews' will be used as the generic term when referring to both focus groups and one-to-one interviews. When required, a distinction between the two types of interviews will be explicitly drawn.

The identification of relevant sites and articles was not conducted methodically, nor was it restricted to any particular period. Instead access to public archives was dictated by online availability as determined by each organisation or publisher. Publications not available online were excluded, i.e. CD-ROMs were not consulted. This effectively meant that only media texts produced post-Dolly (1997) were part of the research data. Cloning stories linked to previous public controversies, such as IVF-related developments in the 1980s, were omitted. A weekly trawl of the internet was conducted throughout the first two and a half years of the research (Autumn 1999 - Spring 2002). After this, only prominent news stories were followed up and printed. This was because the research data had reached saturation point, and for pragmatic reasons relating to the time restrictions for completing a PhD.

2.3.2 Issues of Access

The following section will discuss issues around gaining access to the various groups who offered their help and support to the project. As with many other writings on the research process, this has been written in a one-sided manner and based upon 'hindsight' (see Lee, 1993: 120). That is, accounts of access and non-access are based upon my own 'version' of events with only limited input from those who were contacted and consulted during the research process. My own experiences of gaining access (or not) is illustrative of Lee's argument that there is 'little incentive for a researcher to dwell on the reasons why a request to grant access was refused' (1993: 119). I would extend this to suggest that there is also little incentive to explicitly address why access *was* granted, although during the research process some reasons may be offered. Such an approach is significant in that it is impossible to discuss refused access, beyond the brief comments offered by those acting as gatekeeper, without reverting to speculation.

Further to the limitations outlined above, focussing upon access as separate to the process of conducting interviews or moderating focus groups is a rather artificial distinction. As is clear in the following two sections, albeit to varying degrees, acceptance of the researcher's presence and 'role' in the group is an ongoing process. Access is not only a matter of insiders and outsiders, but also relates to self-presentation, expectations of participants and trust.[3] For the purposes of clarity, however, I will maintain this artificial distinction in order to details the various negotiations which took place.

[3] Each of these are complex and opaque terms and will be clarified in section 2.3.3.

Due to the range of groups approached and the vulnerability of particular groups in this study, the process of negotiating access varied considerably. Although access to patient support groups did not involve gaining approval from the Lothian Research Ethics Committee, there were a number of gate-keeping mechanisms that required negotiation, some of which acted as barriers. Accessing scientists, on the other hand, involved a different set of strategies. In this section I will discuss the range of problems I encountered through a series of access and non-access 'stories' that unfolded as part of the data collection process.

Gaining access to the infertility support groups was obtained by writing directly to the Sister in charge at an assisted conception unit, who, in turn, responded with a letter containing the contact details of two groups in eastern Scotland. I then telephoned the organiser for each group: one was a group run by two patients undergoing fertility treatment (husband and wife), and the other was attached to an assisted conception unit and run by the same Sister.

The patient led support group held meetings every month in a hospital meeting room, and it was agreed with the organiser that I could conduct a focus group with the members at the June 2001 meeting. Prior to the event, the organiser distributed a copy of my research outline to all the members which served two purposes: firstly, to invite those who were interested and willing to attend, and secondly to enable those who did not want to participate to opt-out. This meant that participants were self-selecting rather than the organiser playing any further gate-keeping role. Furthermore, the support group met an hour before my arrival to discuss 'house matters' relating to the groups. This offered the opportunity for those who did not want to participate to leave before the focus group began.

The second fertility support group, held at an assisted conception unit, was organised by the Sister specifically for the purposes of my research. The time, date and venue were set by the Sister and individuals' participation was requested by telephone. Whilst on the one hand, as an 'outside' researcher wanting to gain access to the Unit's support group, the Sister's role of 'sponsor' (Lee, 1993: 131-133) was vital, on the other hand, there were some serious implications around gate-keeping, participant uptake and the actual focus group discussion that emerged.[4] Firstly, that participants were selected by the Sister gave rise to some issues around gate-keeping. I can only speculate about the selection process that occurred because I was not directly involved in the recruitment procedures. It is notable, however, that I was unable to

[4] See the following section for a discussion of the impact of having a 'sponsor' organise and participate in the group discussion.

provide information regarding my research outline to the individuals concerned before the event.

One participant indicated that they had only been asked to participate in the research by telephone the previous evening. Individuals who might have wished to participate were not given the opportunity to attend and those who did were not provided with an outline of my research aims and interests. Within the focus group discussion it became evident that the three female participants were not clear about who I was, what the research was about, or what was expected of them. The outline that they had been given by the Sister had only been verbal (by telephone) and potential participants were not given the time to think it through. In being approached by a person in a position of authority at the conception unit may have had a significant impact upon the participants perception of myself and the research topic.

Identifying patient support groups was achieved through a combination of Internet searches, telephone calls, letters and emails. The approach used for contacting each group was context specific. For instance, when contacting the cardiac support group, I obtained the name and telephone number of the organiser from a poster in the Cardiology Unit within a hospital. I then telephoned the co-ordinator and explained my research interests and wish to conduct a focus group with their members. A time, date and venue was arranged immediately and a follow up letter outlining my research area was sent as a formality. The focus group took place within a room at the Sociology department, University of Edinburgh, due to it being a central and convenient place for participants to congregate and park their cars.

In the case of Diabetes UK, Alzheimer Scotland, Grapevine: Lothian Disability Information Service, Scottish Motor Neurone Disease Association, and the Scottish Huntington's Association, a letter containing an outline of my research and request to conduct a focus group or interviews was sent to the local office.[5] If the address for a local office was not available, I sent my details directly to the national office. Contact with the Parkinson's Disease Society was made using the same letter format, but via an email facility on their Internet site. All organisations initially responded positively except for Grapevine: Lothian Disability Information Service. The reason for this declination was offered by Grapevine's Senior Information Worker: 'Grapevine ... is an advocacy and campaigning organisation. Our members are concerned with challenging local social policy issues, and campaigning against the barriers within society that disable people'. Although my research design did not preclude Grapevine's members

[5] All support groups were asked to participate in a focus group, but I also provided the option of one-to-one interviews, should that be their preference.

participating in the study and members could have offered valuable contributions to the data, such a response suggests that the initial letter sent out to the relevant social groups did not make clear the relevance for talking to them.

A further setback occurred when the Area Project Co-ordinator for a patient support group at Alzheimer Scotland – the 'Saturday Break' group – sent a reply stating that 'this request is probably not appropriate for our group due to the sensitivities of the topic'. The letter went on to recommend that I contact the Head Office, once again outlining my request in order to determine whether there were any other means for gaining access to its members. After contacting the Head Office, I received a telephone call from the project co-ordinator for the Lothian Early Onset Support Service, who agreed to distribute letters to all members. I compiled a more detailed research outline that also contained a description of what to expect when participating in focus groups and interviews. A reply slip with a stamped address envelope was provided. These packages, containing a letter, reply slip and stamped addressed envelope, were sent to seventeen people in total. Of those contacted, five were people with early onset dementia, and sixteen were carers.[6]

I received four reply slips: two from people with dementia – one of whom included their spouse, and two from carers. My next step was to telephone each person to organise a time, date and venue. Upon doing so, the couple (female with dementia and her partner/carer) decided that it would be 'too much and too upsetting' for them to participate in my research. Additionally, one person with dementia did not answer their telephone and had not provided their name and address to be contacted via post. After several attempts and telephone messages, I decided to abandon this interview. Two carers and one person with dementia agreed to participate in my research.[7] Only one person out of three indicated that they would prefer a one-to-one interview rather than to participate in a focus group, I felt that it was inappropriate and unpractical to co-ordinate a joint interview with a carer and a person with dementia.

Both the Scottish Motor Neurone Disease Association and the Parkinson's Disease Society responded positively in the first instance. The former sent a response to inform me that my

[6] A point of clarification: four of the five people with dementia were spouses of carers who were also approached. This meant that one letter and one reply slip was sent asking for either or both to parties to participate.

[7] I would like to note here that the inclusion of Alzheimer's carers in this research is not to provide a proxy voice for people with dementia (see Clarke and Keady 2002). Carers of people with Alzheimer's, instead, have their own set of interests and embodied biographies which are related yet distinct from those of people with dementia.

details had been sent to the Chief Executive for consideration, but no response was ever received. The Parkinson's Disease Society forwarded my details to the Scottish Office. After discussing my research outline with the manager for Scotland, it was agreed that the most promising method of recruitment was to include my research details and request in their monthly newsletter. Whilst in this instance my details reached a greater number of people, the response rate was zero. Again, here, reasons for non-access were not provided, but might include the competing demands upon individuals' time or not recognising oneself or ones own interests within the subject matter of cloning.[8]

I obtained the name and telephone number for the Huntington's Disease support group organiser through the Lothian Advisor for the Society. After a brief discussion about my research topic and methods, the group organiser was extremely positive and invited me to join their monthly meeting where a focus group could be conducted. In the intervening period, all members were alerted to the 'guest' subject for the evening and invited to participate.

Participants from a regional branch of Diabetes UK were contacted via the local office. The Treasurer of the branch put my request to members during a committee meeting. Eight names and telephone numbers of people agreeing to participate were sent by post, following which I was able to co-ordinate a convenient time for five people.

Gaining access to scientists involved a lengthier process and an understanding of the different and relevant kinds of research being undertaken and the relevant actors within the field. Lengthy web searches of media and scientific journals were undertaken as well as conversations with scientists working in the area of genetics, and attendance at relevant conferences with the 'snowballing' that occurs out of such interactions.

---

[8] This latter point was reflected in some of the participants comments in the focus groups and interviews. A number of participants claimed that they had not thought about cloning related issues at any length, if at all. This seems to suggest that their reasons for participating where not due to identifying their own interests in the subject according to the same criteria as used in the research design. For instance, people undergoing fertility treatment did not attend the focus group because they had identified themselves as 'potential embryos donors' and the members of the cardiac support group did not participate because of they recognised themselves as 'potential users of stem cell therapies'. Instead, reasons for attending were stated as being 'out of interest' and also simply because they had been asked, as a way of helping me with my research. It was only a minority of participants who, before attending the focus group/interview, recognised their interests in the same way as defined within the dominant discourses around cloning (see chapter 6).

Due to the high media profile of cloning issues, the individuals within the two institutes which I eventually gained access to – the Roslin Institute and Institute for Stem Cell Research (ISCR, previously, Centre for Genome Research) – receive a large number of interview requests from media personnel and researchers. My experiences of initial attempts to gain access to Ian Wilmut (Roslin Institute) echoed the problems noted by Arksey and Knight: 'leading figures in political, social or business circles ... have little time to spare, do not usually put talking to academic researchers high on their list of priorities, and are protected by lower level personnel' (1999: 122). Whilst gaining access to Wilmut required the greatest degree of persistence on my part (after a series of emails and cancelled meetings), I was permitted to conduct a one hour, recorded interview. Contact with a second scientist from Roslin Institute, John Clark, was gained through a colleague who was a personal friend of the interviewee. In this instance, the initial approach for gaining access was made by a third party who passed on my research details.

I contacted Austin Smith, of the ISCR, via email, providing an outline of my research interests and request to interview him. Smith replied positively, and directed me to his secretary to organise a time and date. It was through Austin Smith that I was able to conduct the joint interview of two researchers from the Institute. Here, my research outline and request for participants was posted by the secretary to each person working at the Institute; only two people responded positively.

When contacting scientists, I pointed out that I had been advised by 'credible' sources, such as MRC Information Officers or other scientists, that they would be useful and helpful participants for my research.[9] This was to present myself as a credible researcher in the context of competing against others (especially journalists) for the opportunity to conduct an interview.[10] That Austin Smith had participated in my research provided helped to gain access to others from ISCR. The advantages of utilising snowballing techniques, however, may be questionable due to the low response rate to my interview request at the Institute for Stem Cell Research. We might speculate that non-access was due to a number of issues around work pressures, busy lifestyles etc. Equally, based upon other researcher's experiences in interviewing scientists (or elites more generally), explanations may be due to the research method that I had adopted. For individuals

[9] Here, 'credible sources' refers to individuals associated with organisations (such as the MRC) or professions (such as scientists) that have, traditionally, come to be recognised as producing or sanctioning 'knowledge'. More specifically, these are sources that are likely to be recognised by interviewees as relevant and credible sources to their particular field of work; hence, individuals from the MRC.

[10] For a brief discussion of the uses of gaining a 'competitive advantage' in the context of access to elites, see Puwar (1997).

working within scientific traditions, the value of the methodological principles and research agenda of social scientists may easily be dismissed unless they are clearly embedded within the professional (or personal) lives of scientists (see Puwar, 1997: 5.3). My junior status as a researcher may have further exacerbated the problem.

2.3.3 Conducting Focus Groups and Interviews: Introduction

Within the following discussion, I will consider a number of issues that arose during the process of conducting interviews and focus groups. Firstly, providing examples, I will focus upon some general issues that relate to the methods utilised. Secondly, I will address some differences between the process of conducting focus groups and one-to-one interviews. Thirdly, I will go on to discuss two particular encounters that occurred in one focus group and one interview. These were problematic instances within the data collection process, where a number of issues that were pertinent throughout the research were heightened.

2.3.4 Developing a Topic Guide

Before conducting either the focus groups or interviews, I developed a topic guide for the different groups to be included. Given that I was not aiming to standardise the research design across different constituencies, I did not attempt to develop a set of universal questions or prompts. Instead, the topic guide was developed as an *aid memoir* of themes that I wanted to cover during the discussion. The topic guide was sufficiently flexible in terms of the time allocated to each theme and the order it was addressed to allow the discussion to be guided by participants' interests. Furthermore, the *aid memoir* was not intended to place boundaries around what could or could not be discussed, but instead served as a 'safety net' or checksheet to ensure that I had not missed anything vital to the study. The same topic guide was used for both the focus groups and individual interviews on the grounds that both the group and one-to-one interviews aimed to address my research questions in a dialogic manner that was relevant to participants. At the end of each interview or focus group discussion, participants were asked to complete a form to provide biographical details, including age, religion, relevant interest to this topic (i.e. medical or professional). It was made clear that there was no obligation to complete all, if any, questions.

2.3.5 Group Size, Composition and Setting

According to most accounts, the ideal focus group size should be between four to ten people (see, for example Kitzinger, 1996), and researchers are advised to slightly over-recruit to obtain the optimal group composition. However, when accessing patient support groups – pre-existing groups – the group size was found to be beyond my control. Whilst when initially contacting support group co-ordinators I had outlined the ideal number of people to be involved, in practice, the number of people that came varied. The variability was influenced by a number of factors, including how many people would ordinarily attend the support group meetings, how the co-ordinator 'advertised' and recruited members for the discussion, as well as individual contingencies such as work commitments (see section 2.3.2).

The size of the focus groups ranged from four to eighteen. The largest group, Huntington's Disease support group, consisted of a relatively large number of regular attendees. That the focus group was conducted as part of the monthly meeting meant that I was unable to influence the size. Equally, the cardiac and patient-led infertility focus groups were conducted as part of their monthly meeting, resulting in group sizes of ten and seven respectively. The remaining focus groups (infertility and Diabetes support groups) were organised specifically for the purposes of participating in the research.

As with size, the group composition was also variable. All of the support groups consisted of a combination of people with the condition/disease in question, along with family members and interested individuals. For instance, one infertility support group contained a senior Sister, and some participants in the cardiac support group had family members with them who had driven them to the meeting. The Huntington's support group included individuals 'at risk' of developing the disease,[11] spouses, a health advisor, and a retired scientist who had spent much of her carer conducting research into treatments for Huntington's disease. It is also notable that some members of the cardiac and Diabetes support groups were the spouses of people who had died from these conditions and one man had a son living with Diabetes. Whilst all participants had vested interests in the organisation to which they belonged, those interests were heterogeneous.

[11] There were a number of younger people in the group, and it was not disclosed whether they had been tested for the Huntington's disease gene, or the outcome of that test. Therefore, 'at risk' means that they have a parent who carries the gene who may or may not have been alive.

The interviews took place in a range of venues. Focus groups with the cardiac and Diabetes support groups took place in Edinburgh University rooms, as this was the most convenient option for the participants. The co-ordinators for both infertility support groups and the Huntington's Disease support group arranged for the focus group to take place at the same venue in which they hold their meetings: hospital meeting rooms and a church hall. The first one-to-one interview with an Alzheimer's carer took place in his office, and the second in her home. In the case of scientists, all one-to-one interviews were conducted in their offices, and the two-person interview with research students took place in the university canteen.

2.3.6 Developing a Dialogue

When entering each interview (group and individual), I had two sides of A4 paper containing a 'map' of areas that I wanted to cover (the *aid memoir*). Before the interview began, I explained the aims of the discussion and how it fitted into my research, outlining the themes that I wanted to cover.[12] I then requested to tape-record the discussion and assured individuals that they would remain anonymous, except for the three prominent scientists who spoke 'on the record'. For most of the interviews these issues had already been addressed as part of gaining initial access, however, I considered it important to go over why I wanted to speak to them. Explaining the aims of the focus group or interview at the outset enabled individuals to ask questions and opt-out should they wish (nobody did). This was useful in partly overcoming the problem of consent in the Sister-led infertility support group.

The way in which I introduced myself and the project area differed, depending upon the group or individual in question. The greatest difference was between the scientists and non-scientists. For instance, with the support groups I could not assume that participants were familiar with technical descriptions of cloning techniques or had thought about cloning prior to the event. One of the early prompts was to ask 'What kinds of ideas or images come to mind when you think about cloning?'. With scientists, however, an initial prompt was to ask them about their involvement in, and thoughts on the SCR and human cloning debates. To have asked a general question about their thoughts on cloning would have been inappropriate as it is likely to have

[12] I broke the themes down into three distinct areas: 1. Views and perceptions of cloning 2. Views and perceptions of science, technology and medicine 3. How these developments impact upon people and society, and their views on this.

elicited a 'technical' or normative response. When preparing for each interview or focus group, therefore, I adjusted my agenda, language and self-presentation[13] to suit the context.

In interviews with non-scientists, participants said that, prior to being invited to participate in the research, cloning had not been a topic of discussion during support group meetings. Many individuals claimed that they had not explicitly thought about SCR and cloning before – this was their first opportunity to consider and articulate their views. So, whilst participants had been identified as being implicated in cloning developments, it was evident that this did not reflect the way in which *they* located themselves in relation to the subject matter. Instead, cloning was a topic regarded as tangential to their own lives, albeit, an interesting one. Whilst this is the general pattern that emerged at group level, there were individuals within the groups who deviated from this. For example, in the Diabetes support group one participant had 'prepared' for the discussion by searching the Internet, and in the Huntington's Disease focus group a number of participants remembered parts of a talk on stem cells they had attended.

Participants from the various support groups were often exploring and constructing their views on SCR and cloning *during* the interviews; this meant that they had as many questions as views on the topic. These questions were both about each others views as well as about scientific practices. Despite introducing myself as a non-scientist, many participants asked difficult questions about various aspects of SCR and the cloning technique. There were a number of questions that came up in every group, such as the difference between 'therapeutic' and 'reproductive' cloning, the technique used for cloning Dolly the sheep, and UK policies on SCR and reproductive cloning. Additionally, there were questions that were often more particular to the group. To have avoided these questions would have had detrimental effects upon the interviewer-interviewee relationship in terms of trust and rapport. In conceptualising the interview process as a dialogue, it was important that I engaged in an open and active exchange with participants where appropriate, thus bringing 'double subjectivities' into the research process (Lewis and Meredith, cited in Edwards, 1993: 185).[14]

---

[13] Self-presentation here refers to the different personas that the facilitator/researcher adopts (Kitzinger and Barbour, 1999). The self-presentation or persona of the researcher is constructed relationally. For instance, when interviewing scientists I had to negotiate my persona as a non-scientist that was also distinct from that of journalist – a group with whom many of the scientists were used to dealing with when discussing social or ethical issues. However, when interviewing patient groups I had to negotiate my identity as a non-scientist, even though many participants addressed me as though I was a scientist (i.e. asking scientific or technical questions).

[14] Double subjectivity involves the inclusion of the researcher in the research process and analysis, as opposed to claims of objectivity. Also known as 'dialogic retrospection', double subjectivity refers to an approach where, 'Instead of seeing people in the research process as simply sources of data [the] research process is a two-way process' (May, 1993: 14).

Although I did not attempt to adopt the role of scientist, I did provide responses based upon the knowledge that I had acquired whilst conducting the research.[15] When providing answers to some of their questions, I also offered an account of my experiences and difficulties with understanding and keeping up with the scientific and technical aspects of this area. It was important to include myself within the research topic and to reciprocate with a certain amount of self-disclosure. In doing so, this begin to facilitate a discussion that went beyond the scientific and technical information, but also enabled participants to incorporate some details provided into their discussion. Although the focus of the research was not to 'test' participants on their technical or scientific knowledge of cloning, on reflection, it was naïve to assume that such information would not be needed. When asking participants to engage in a discussion where they reflect upon their, as yet, unformed views on cloning, it might have been helpful to have produced an information pack of websites, articles and contact sheets for them to take away.

2.3.7 Conducting Focus Groups With Pre-existing Groups

By accessing pre-existing, or 'naturally-occurring' groups, particular methodological issues emerged from the discussion process.[16] On the one hand, all participants knew one another and were familiar with the group norms and dynamics. This familiarity meant that participants had already established a rapport and they engaged in friendly banter. Rather than having to spend time 'warming' the group I was able to go over the 'ground rules' of participating in focus groups and then introduce the topic of cloning within a safe environment. On the other hand, however, the boundaries around the sorts of issues that can and cannot be discussed and who the nominated speakers are, are often already established and entrenched. As Kitzinger and Barbour argue: 'the researcher should consider how the group context and broader cultural and institutional features operate to encourage or suppress the expression of certain points of view' (1999: 8). That the group convened around one common interest (e.g. Diabetes), served as the dominant shared identity. Whilst this does not necessarily close off other non-shared identities within the group, such as gender or religion, the established norms and hierarchies do have an impact upon contributions offered.

---

[15] It is important to note here, that as the project developed over time, my understanding of cloning practices increased and, therefore, I became better equipped to answer questions in later interviews than the earlier ones.

[16] 'Naturally-occurring' groups is a term widely used within literature on research methods. A more appropriate term for patient support groups, however, is 'pre-existing' groups.

In the Diabetes support group, for instance, one participant (identified as DM2) arrived at the group with some Internet articles containing quotes from Ian Wilmut. It was evident that DM2 was the nominated speaker within the group hierarchy, perhaps due to the absence of the usual group co-ordinator. Within the group discussion, arguments made by Ian Wilmut within the article were invoked by DM2 as 'legitimate' knowledge which inhibited the contributions of other members. In particular, arguments proposed by the two women in the group – that women might have a different relationship to embryos than men – were readily dismissed as irrelevant (see chapter 7). By aligning the concerns of Diabetics with 'expert' knowledge, DM2 was able to (re)establish a boundary around what sorts of issues were seen as relevant to the group, thus suppressing the expression of the points of view of the women. In a different context, the views of one woman who was expressing her concerns about cloning were suppressed through humour. Instead of engaging with her and discussing her views on reproductive cloning, another participant responded "but then there'll be two people making the tea at the meetings".

2.3.8 Conducting One-to-One Interviews

Whilst holding focus groups was the preferred method of data collection, one-to-one interviews were used for pragmatic reasons (e.g., they felt uncomfortable speaking in a group situation, or logistically difficult to co-ordinate a group of people who have many demands on their time). All participants were asked to participate in a focus group but were given the option of a one-to-one interview if preferred.

As already noted in section 2.3.2, it was not possible to gather enough people from the Alzheimer's Society to constitute a focus group. Subsequently, I conducted two one-to-one interviews with Alzheimer's carers but used the same topic guide used for focus groups. Whereas in the focus group discussions participants engaged in a dialogue between each other (and occasionally, myself), in the one-to-one interviews my role was slightly different. Rather than simply facilitating the discussion and allowing participants to prompt each other, in the interviews I had to generate a dialogue between myself and the participant. Here, the presence of double subjectivity in the research was more apparent. That is, the interview was more of an dialogic process and participants' accounts were 'the result of their interactions with me' (Edwards, 1993: 185). As in the focus groups, however, participants also 'tested' ideas during the interview, such as starting sentences with 'I haven't thought this through but ... '.

Another significant difference of one-to-one interviews compared to focus group, was that participants provided personal, biographical 'stories' about their lives and experiences. Both interviews involved lengthy conversations about an individual's experience of being a carer for somebody with Alzheimer's Disease, including stories about diagnosis, relationships with clinicians and other family members. Such sensitive moments of disclosure did not occur within the infertility or patient support groups.

When interviewing scientists I also conducted unstructured conversation-based interviews around the topic guide. After gaining access to scientists working in the area of SCR and/or cloning, there were a number of issues that arose when conducting the interviews. The main issue involved developing a rapport with the individual in order to get beyond the accounts available in the media. All prominent scientists were accustomed to dealing with journalists and their style of questioning; this meant that it was difficult to get beyond the initial façade. This was perhaps due to a lack of trust that the scientists had developed in relation to a sensationalist press that tended to de-contextualise quotes. As a young social scientist, however, it was difficult to successfully develop a rapport in one hour.

Attempts to get beyond stock phrases and the party line were made by engaging the scientists in a dialogue, asking them how they would respond to alternative assertions or arguments to their own. They were also asked to reflect upon how the debates have or may have an impact upon their own views or practices. One participant, in particular, was very cautious with language and phrasing. It was suggested by another scientist who overheard part of an interview[17] that my style of questioning, as a social scientist, differed to the style that they had become accustomed to with journalists; this may have been interpreted as a ploy to 'trick' the person being interviewed. On reflection, this occurred in the interview with Austin Smith. The wording of one question resulted in him turning his chair away from me while he considered his response. He then provided a cautious answer before I reworded the question and explained that I wasn't trying to 'trick' him.

In focus groups with infertility and patient support groups I was able to continue with the discussion beyond one hour. With two of the scientists, however, it was clear that there were more pressing time constraints and I was restricted to one hour. I had to behave more like a journalist, and simply switch on the tape recorder and then launch into the interview (see Puwar,

[17] When conducting the interview with Ian Wilmut, another scientist/science communicator who shared the same office was moving in and out of the room.

1997: 7.1). The final one-to-one interview and the two-person interview were more relaxed, and the discussion was allowed to continue for an hour and a half, and two hours respectively. One final point here is that in one case, the formal interview lasted under one hour, after which I thanked the participant for their time and turned off the tape recorder. After this point, the conversation then became much more open and continued for another three quarters of an hour. It was only at this point that the participant began to fully engage with my area of research and offer some insightful comments. I noted these down on paper afterwards, rather than having them on tape. These 'off-the-record' comments have not been used in the thesis but instead added to my stock knowledge of SCR and cloning – as defined by a key scientist.

2.3.9 The Presence of Authority

As described in the previous section, access to the support group within the Assisted Conception Unit was achieved via a sponsor. It has been noted by Morgan and Krueger that the involvement of sponsors or 'other influentials who want to handpick the participants' can, potentially, jeopardise the focus group process (1993: 10). They go on to suggest that interference by sponsors is reason *not* to use focus groups (Morgan and Krueger, 1993: 10). In reflecting upon this focus group experience, however, I would suggest that the involvement of sponsors can be both prohibitive and generative.

During the early stages of the infertility focus group discussion, it became clear that all three participants had been contacted to request participation only the evening before. It also became evident that they were unsure what research they had consented to participate in. Whilst they knew the subject was SCR and cloning, they had not received a copy of the research outline. As the researcher and focus group moderator, initiating a focus group discussion on a sensitive topic with a group of participants who had not been provided with the full information was an uncomfortable position to find oneself in. I was unprepared for such an eventuality at this early stage in the data collection phase (second focus group), and found myself having to provide a research outline 'on the spot'. In doing so, however, I was able to ensure informed consent.

The second, and perhaps most significant methodological issue relates to the Senior Sister's presence in a group discussion. After the participants had arrived the Senior Sister then stated that she would like to sit in on the discussion as she was interested in the topic. As a young researcher with little experience of conducting qualitative fieldwork, I had not anticipated such a request and felt obliged to agree. When introducing my area of research and the topics to be

covered during the discussion, the Sister interrupted to ask that I explain the difference between 'therapeutic' and 'reproductive' cloning to the group. She then went on to describe the distinction according to her own view. From the outset, she asserted herself as a dominant figure, controlling the tone and content of the discussion.

The result of the Sister's interventions had a direct impact upon the discussion. For instance, participants often addressed their views to her rather than one another or myself, which was indicated in their body language as well as verbally. During the discussion it was clear that the power relations between Sister and patients affected their experiences of participating in the discussion. Compared to the patient-led infertility support group, there was a reticence to critically discuss issues around cloning that relate to their experiences of assisted conception. This can be attributed to the way in which the Sister managed aspects of the discussion that directly related to practices in the clinic. For example, issues around embryo donation, consenting procedures and meanings around stem cell research were areas where critical voices were silenced through the Sister's interventions.

The presence of the Sister, however, was not an entirely destructive one but also added an extra dimension to the discussion. After the initial ice-breaking period, the Sister participated in the focus group, providing her own views on cloning related issues and leading the discussion into difficult areas for discussion such as issues around the role of corporations in stem cell. Whilst it was difficult for me to manage the complex power relations between researcher-researched alongside that of Sister-patient and sponsor-researcher, the power dynamics between herself as Senior Sister and the three patients was obviously a relationship that she had experience in managing. This meant that the Sister maintained the discussion, offering some interesting views as well as managing areas that related to practices at the clinic.

2.3.10 A Failed Interview

Including the perspectives of people with dementia in social research has long been regarded as an ethically sensitive task (see, for example, Wilkinson 2002). As shown in the previous section, negotiating the various layers of gatekeepers when gaining consent is problematic in itself. The process of conducting interviews with people with dementia adds another layer of methodological issues. The following discussion revolves around conducting an in-depth interview with a woman with dementia. This interview, as intended, was brought to a halt and the content were not used within this thesis.

As already indicated, access to people with dementia and their carers was gained through Alzheimer Scotland's 'early onset support group'. When I telephoned Ms. R she had not remembered replying to my initial letter and was unaware of why I was contacting her. I explained that I was interested in hearing her views on cloning and clarified my identity as a researcher from Edinburgh University. Ms. R gave her consent to be interviewed and we established a time and date for me to go to her home. In the meantime I sent another copy of the initial letter and a covering letter stating the time and date for the interview, asking her to contact me should she change her mind. Upon arriving at her home, she was sat in the dark, with the curtains closed and the radio playing very loud. I asked again if she understood why I was there and whilst she knew that I wanted to ask her some questions, she was unsure what they were and was confused about my identity. As the interview began, it became clear that she did not realise that I was a university student, but thought I was a support worker from Alzheimer Scotland.[18] When I tried to explain who I was and introduce the topic of cloning, this seemed to further confuse her and led to a brief demonstration of agitation.

When I asked some ice-breaking questions about herself, she replied that she did not have Alzheimer's disease, but a different form of dementia called Pick's disease - an incurable condition that her sister had died from six months earlier. Upon mentioning her sister, Ms. R became upset, explaining that she was still mourning her sister's death and was extremely lonely and frightened. At this point I stopped the tape-recorder in order to allow Ms R to find some tissues, and to assess whether I could continue with the interview. Throughout the following conversation I attempted to introduce the topic of cloning; however it was evident that she was confused and agitated by this. For instance, it was notable that she often responded with "yes" or "no" inappropriately to questions that confused her.

When involving patients with dementia, the complexity and importance of conceptualising consent as an on-going process is heightened. In this particular instance, I was acutely aware of my responsibility to protect the welfare of the participant, especially given that she had no family support around her. It was apparent to me as a researcher that even if she had offered any views on cloning, it would have been unethical to include her comments in the thesis. This is largely due to it being unclear whether she understood who I was or what she was contributing to.

---

[18] Ms R was accustomed to having community workers and volunteers coming to visit her and seemed to ascribe a similar role to me. When I explained that I wasn't *from* Alzheimer Scotland she appeared confused, but was then happier when I said that I had contacted her *through* the organisation; thus, establishing a degree of trust.

2.4 Data Analysis

As noted in section 2.2, data collection and analysis were not distinct phases, but instead were iterative and co-constructive. Analysis of parliamentary debates, media texts, official reports, interviews and focus groups was conducted in parallel as an ongoing feature of the research process, and, therefore, fed into one another. In this sense, the data collection and analysis was characterised by a steep learning curve. Within this section I will outline some of the key features involved in analysing my data.

2.4.1 Identifying Discursive Regularities and Recurrent Themes

In keeping with the approach of Mulkay et al. (1983), I explore the recurrent interpretive practices employed by a range of actors across different social contexts (see also, Mulkay, 1993). This means that, firstly, I recognise that people portray their actions and beliefs in different ways depending upon the broader context. For example, scientists utilise different discourses and repertoires in formal literatures (such as journal articles) compared to informal discussions in the laboratory or within interviews with social scientists. Similarly, patient groups will present their beliefs differently and draw upon different discursive repertoires when in the company of clinicians (see 2.4.9) compared to when in the company of other patients, family or friends. Discourse analysis, then, is a useful tool for identifying the range of repertoires, devices and cultural resources employed by actors within their accounts of SCR and cloning. To this extent, my analysis aims, not to explain how science 'really operates' or a definitive account of how relevant social groups view SCR and cloning, but to provide an interpretive reading of their readings.

A further but related point of clarification corresponds to the identity of actors vis-à-vis the context within which the 'data' was generated. Social context constrains as well as enables particular accounts of the world and people's accounts should always be treated as partial or even provisional. As already outlined within this chapter, identities are multiple and flexible, and contexts such as the Diabetes support group generates a particular shared identity amongst members that excludes other aspects of ones identity. For instance, the needs of people with Diabetes as 'patients' are foregrounded over gender. This is not to say that other identities do not seep in to the patient group context, but that the social context and data collection methods

used impact upon the nature of data obtained. The aim of the research was not, however, to understand any one persons understanding in detail but to understand *how* people negotiate human cloning rather than answering *why* a person has any particular view or opinion. Furthermore, such an approach is indebted to cultural studies research that conceives the self as a process of *becoming* rather than *being*: the self is not a unified or finalised entity, but a project to be worked on, negotiated and contradictory. This is also to say that I could not claim to have only witnessed one particular social role, such as being infertile of having Huntington's, but that identity formation and negotiation is a messier activity where different social roles are brought to bare, if only momentarily upon the situation.

2.4.2 Coding: Manual and Computer Aided

Transcripts from the parliamentary debates were coded manually, using coloured pens and "post-it notes". After reading through the transcripts a number of times I identified what Mulkay calls 'discursive regularities' (1993: 723). These are the discursive repertoires that reflected the recurrent themes, ideas, assumptions and discourses mobilised during the parliamentary debates. In order to identify themes and discursive regularities, related material – such as official documents, media reports and informal discussions with relevant actors (see section 2.3) – informed the coding system for the Hansard transcripts in a non-formalised way.

Following on from this, analysis of interview and focus group transcripts followed a similar pattern of reading, note-taking, and comparisons between my data and other analyses of scientists and publics' discourses (for example, Kerr et al., 1997; 1998a; 1998b). However, rather than coding the interview and focus group transcripts manually I used the QSR NUD*IST data analysis software for creating coding systems and analysing data. Here I created a simple coding structure, identifying recurrent themes (such as distinctions between 'reproductive' and 'therapeutic' cloning and constructions of expertise) as well as distinct issues (such as issues of patenting or the use of embryos for SCR). Within these codes I then looked for rhetorical strategies and repertoires mobilised by actors as well as deviations. All coded data was then printed and coded in more detail manually. The combination of the software package and manual coding helped me to gain a deeper understanding of my data and to compare excerpts from transcripts.

2.4.3 Presentation of Data

Throughout the thesis I have used quotes from interviews and transcripts to illustrate analytical points and to describe certain issues. Underpinned by the epistemological approach for allowing people to articulate their views 'in their own vocabulary, generating their own questions and pursuing their own priorities' (Kitzinger, 1996: 68), I have incorporated a large proportion of the interview material into the following chapters.

Quotes from the three key scientists are directly attributed: Austin Smith (Institute for Stem Cell Research [ISCR]), Ian Wilmut (Roslin Institute) and John Clark (Roslin Institute). The joint interview with two research scientists are represented as RS1 and RS2. Quotes from support groups are attributed using shorthand codes:

F1 = Patient-led infertility support group
F2 = Sister-led infertility support group
C = Cardiac support group
H = Huntington's Disease support group
D = Diabetes support group
AC1 = Alzheimer's Carer # 1
AC2 = Alzheimer's Carer # 2

And within each focus group, individuals are identified according to their sex (M = Man; W = Woman) and numbered in order of appearance within the discussion, for instance, the second man to speak within the cardiac support group is identified as CM2 throughout the thesis. The dates when each interview took place are also noted.

2.5 Reflections on Research Process and Limitations of Study

The methods used for data collection and analysis were selected for their appropriateness to address the research questions outlined in Chapter 1 (section 1.2). A thematic analysis of parliamentary debates on SCR and cloning allowed me to identify the range of issues pertinent to these developments, to locate dominant discourses and voices within the debates, as well as to reveal groups whose voices were rhetorically invoked but not included. I concurrently keep an eye on media commentaries of this area, cross-comparing the recurrent themes emerging in each. This helped me to gain an insight into the breadth and depth of public debates on SCR and cloning and to identify which actors were included or excluded. Analysis of parliamentary

debates also provided the groundwork for identifying the range of issues raised by this area of research, which could be further explored within the focus groups and interviews with relevant social groups.

In order to get behind the way the issues were framed in Parliament, I chose to conduct focus groups with scientists working in the field of SCR and/or cloning, patient support groups and infertility support groups. These groups represent both dominant and marginalised voices within the debates. To conduct focus groups allowed participants to articulate their thoughts and views on this area according to their own terms of reference, outlining what was, for them, the key issues. Other than the problems outlined above (see section 2.3), this method worked very well for patient support groups, revealing how people's views are shaped by embodied experiences and social location.

Attempts to conduct focus groups with scientists working in the field of SCR and cloning, however, were unsuccessful. As discussed in Section 2.3.2, gaining access to scientists was very difficult and I had to conduct individual interviews with three scientists and a joint interview with research scientists. It had been hoped that focus groups with scientists would create a similar group dynamic as in the patient support groups. My analysis would have profited from gaining access to a group of scientists engaged in a discussion about their work, their views of the social implications of SCR and cloning and science-public relations. Whilst one-to-one interviews did permit an insight into these aspects, the discussion was limited because I could not explore the everyday uses of language and communication.

Using focus groups did, however, limit the data obtained. For instance, within the patient support groups, I was unable to gain an insight into the details of people's biographies because focus groups do not allow for such personal discussions. Since one of my key analytical points was to ascertain how people's biographical and embodied experiences shape their views, this limited the strength of my argument. A further problem was generated by the open-endedness of the topic guide used. Because I allowed people to generate discussions that were pertinent to their own experiences and views, this meant that each group tended to foreground different issues. Subsequently, some of my analysis is based around data from one focus group rather than being able to cross-compare with those in other groups.

Because of the timing when all interviews and focus groups were conducted, if I were to repeat this study again, I would expect to obtain different data to that presented in this thesis. Data collection was conducted between May and November 2001 – the period immediately after the

amendment to the HFE Act (January 2001) and before any scientists had received a license under the new regulations to conduct SCR in this country. The SCR and cloning debates were, therefore, novel to non-scientists who were often discussing their views for the first time during the focus group and interviews. Two years on, SCR and cloning stories and 'breakthroughs' are becoming increasingly commonplace, *suggesting* that processes of entrenchment are underway. My research is unable to show any changes that may have occurred since the new regulations came into place, such as changes in public opinion or that of scientists. Furthermore, because some of the participants had never discussed their views of SCR and cloning before, this thesis is a snapshot analysis of their 'first thoughts'. I would expect their views to have altered since then and to conduct follow-up focus groups and/or interviews would be an interesting future project.

CHAPTER III

The Politics of Cloning: Mapping the Rhetorical Convergence of Embryos and Stem Cells in Parliamentary Debates[1]

3.1 Introduction

Whilst human embryonic SCR has been carried out since the mid-nineteen nineties, it was not until after the birth of Dolly the sheep that the Government formerly addressed policy issues surrounding related developments. Between 1997, the year Dolly was announced, and early 2001, the Government commissioned a consultation paper by the Human Fertilisation and Embryology Authority (HFEA) and the Human Genetics Advisory Commission (HGAC), and established an expert advisory committee headed by the Chief Medical Officer, Professor Liam Donaldson. The outcome of these papers was a proposal to amend the existing 1990 HFE Act, that culminated in a series of parliamentary debates to decide upon the future of SCR. The proposed amendment would add a further three categories for embryo research to the existing five.[2] The amendment was passed in a non-party vote in the House of Commons with 366 ayes and 174 noes, then passed to the House of Lords who divided with 212 ayes, and 92 noes.

As in the debates that led to the establishment of the 1990 HFE Act, the stem cell debates demonstrated that there is still no consensus as to the moral status of the embryo. Indeed, it appears that recent developments in cloning and genetic technologies have further problematised questions of life as they relate to embryo research. The significance of Dolly was not the ability of scientists to clone *per se*, but the demonstration that cells taken from an adult mammal could be 're-programmed' - a process called de-differentiation - to produce a genetically identical copy of the original.[3] If adult cells can be de-differentiated, then this offers

[1] A version of this chapter has also appeared in *New Genetics and Society*, Vol. 22, No. 2 (2003), pp. 145 – 168. See Appendix I.

[2] Existing regulations permitted embryo research that related directly to reproductive medicine: contraception, miscarriage, infertility and the detection of abnormalities prior to implantation. The three added categories were as follows: i) to increase knowledge about the development of embryos ii) to increase knowledge about serious disease iii) to enable any such knowledge to be applied in developing treatments for serious disease (HFEA Code of Practice, Fifth edition, April 2001: 53)

[3] De-differentiation was the initial term used by Ian Wilmut to describe the technique used for cloning Dolly the sheep. This is where cells that have become specialised, such as skin or

new avenues for scientific research to understand not only how cells become specialised, but also how to control that process. Consequently, we have seen speculation regarding a number of applications, including reproductive cloning, stem cell therapies and xenotransplantation.

This chapter examines some of the rhetorical resources and strategies used during the stem cell debates vis-à-vis analyses of the pre-1990 embryo debates. I will draw upon my analyses of three Hansard transcripts of stem cell debates: two from the House of Commons (17 November and 19 December 2000) and one from the House of Lords (22 January 2001). By focussing upon what Mulkay calls 'discursive regularities' (1993: 723), I map the contours of the debates that dominated discussions of stem cell cloning in Parliament. I have not focussed upon the specific accounts of individual speakers, nor provided a comprehensive comparison of the broadly pro-eSCR and anti-eSCR arguments.[4] Instead, this chapter identifies discursive regularities of the stem cell debates comprising typical assertions that reflected the recurrent themes, ideas, assumptions and discourses that were mobilised during Parliamentary discussions.

Discussion of the embryo debates during the 1980s is enabled through a selective comparison to analyses conducted by Michael Mulkay (1997), Sarah Franklin (1997, 1999), Marta Kirejczyk (1993, 1995, 1999) and Patricia Spallone (1986, 1989). In comparing the 'recurrent interpretative practices employed' (Gilbert and Mulkay, 1984: 14) by parliamentarians during the 1990 HFE Act debates with those of the stem cell debates, I will identify the discursive points of convergence. The form and content of SCR and cloning related developments are shown to be constructed according to pre-existing sociocultural discourses that reveal the 'interrelated set of background assumptions' of the speakers (Mulkay, 1993: 723).

3.2 Managing the debate: Scene Setting and Lobbying Prior to the Parliamentary Debates

The announcement of Dolly the sheep in February 1997 opened the floodgates for debates on the implications of the growing biotechnology industry for humans and society. Religious leaders, politicians, patient groups, scientists and non-affiliated individuals, have voiced their particular perspectives on the subject. In response to the escalating public debates, in 1997 the

---

nerve cells, are re-programmed in order to become any cell type. However, Wilmut has since questioned the accuracy of this term, in suggesting that cells never fully differentiate to begin with, hence retaining their capacity to be re-programmed (see Franklin, 2001a: 7).

[4] I have used the 'pro' and 'anti' research labels as shorthand for the purposes of this chapter. Whilst the debates were not entirely polarised around two positions – with individual speakers inhabiting complex and often contradictory positions – the debates were often structured around Parliamentary conventions: a vote of either for or against.

Human Genetics Advisory Commission (HGAC) and the Human Fertilisation and Embryology Authority (HFEA) held a joint consultation exercise resulting in a published report, *Cloning Issues in Reproduction, Science and Medicine* (January 1998). From this very early stage in the public debates there emerged signs of the rhetorical severing of therapeutic cloning from reproductive cloning. Whilst it was recommended that reproductive cloning should remain illegal, and required primary legislation to explicitly ban it, therapeutic cloning was deemed to hold the promise of medical benefits. This distinction lay in the intention and purpose of the research rather than the cloning technique per se. It was considered that the uses of reproductive cloning would be unethical, unsafe and inefficient as a means for human reproduction. Therapeutic cloning, however, was not considered to produce the same ethical problems as cloning whole human beings. That therapeutic cloning is the use of cloning techniques for potentially curing a multitude of diseases was an important aspect of the argument for separating the ethical issues of reproductive cloning from this 'benevolent technique'. Furthermore, in an attempt to avoid the stigma of the word 'cloning', the HFEA/HGAC report changed the terminology from 'therapeutic *cloning*' to 'therapeutic uses of *cell nuclear replacement*' (my emphasis).

The HGAC/HFEA report advised government to extend the HFEA regulations to include two further purposes for research: 'developing methods of therapy for mitochondrial diseases and developing methods of therapy for diseased or damaged tissue or organs' (1998: 9.3). The government responded to this report in June 1999 by establishing an expert advisory group, the Donaldson committee, to consider the proposed changes to the HFE Act that would allow SCR with a view to developing therapeutic uses of cloning techniques.

Between 1999 and the Parliamentary debates in late 2000, numerous science-based organisations published reports and press releases in the UK explicitly outlining their position on the matter of cloning and its applications and implications for humans. These include the Nuffield Council on Bioethics, Royal Society, Medical Research Council (MRC), British Medical Association (BMA) and the Association of Medical Research Charities (AMRC). The report of Donaldson Committee, *Stem Cell Research: Medical Progress with Responsibility* (Department of Health, June 2000), opened by focussing upon the distinction between reproductive and therapeutic cloning. Stem cell research using cloning techniques was supported for therapeutic purposes, organisations such as the BMA stated that they remained 'resolutely opposed to the cloning of whole humans' (BMA press release, 24 June 1999). Whilst identifying various ethical problems caused by the prospect of cloning humans, such as the devaluation and commodification of life, therapeutic cloning was constructed as presenting no new ethical dilemmas. These arguments were based upon the grounds that the aims and objectives of the research and its potential

applications differ: one aims to provide treatment for a variety of diseases and conditions whilst the other aims to produce a cloned human. This position, as advocated by science-related organisations, was endorsed by the Donaldson Committee's report which clearly separated reproductive and therapeutic cloning mobilising arguments outlined by the pro-eSCR lobby.

Initial public responses to the development of cell nuclear replacement, the technique used to clone Dolly, were captured in the Wellcome Trust's study *Public Perspectives on Human Cloning* in 1998. Issues covered by the focus group participants addressed a broad range of social, moral and ethical problems that cloning poses for individuals and society. These included, for instance, the potential stigma attached to being a cloned human being, kinship issues and the effect of cloning on sexual relations and procreation. In discussing cloning, participants also expressed concerns relating to eugenics, genetic engineering, uses of embryos for scientific experimentation and the regulation of scientists and scientific research. The initial post-Dolly report from *The Wellcome Trust*, thus, indicated a more widespread feeling towards cloning and biotechnology which was, at worst, antipathy and, at best, ambivalence (1998).

Within the Parliamentary debates, public anxieties around cloning developments were translated into an emerging 'anti-science climate' in the UK, by speakers from both sides such as Yvette Cooper[5], Baroness Warnock[6] and Lord Alton[7]. After the high profile media coverage of recent controversies, such as BSE/CJD and GM foods, science-public relations were perceived to be increasingly under strain. For those in favour of SCR, the emerging anti-science climate was identified in order to suggest that anxieties surrounding SCR could be attributed to the broader 'mood' (see, for example, Yvette Cooper, HC 17 Nov 2000: Col 1228-1229). Indeed, Baroness Warnock believed that fear and suspicion towards scientists and politicians has reached 'dangerous proportions', and subsequently went on to argue that:

> We are becoming a nation of cynics who cannot believe anything that they are told and who suspect the evidence and the motivation of the people who produce it. This is a situation that we ought to fear (HL, 22 Jan 2001: Col 43).

---

[5] Yvette Cooper was the Parliamentary Under-Secretary of State for Health and an advocate for stem cell research and the proposed amendment to the 1990 HFE Act.

[6] Baroness Warnock, a pro-research advocate and moral philosopher who chaired a committee of inquiry in 1982 to 'examine the social, ethical and legal implications of recent, and potential developments in the field of assisted [human] reproduction' (Warnock, cited in Mulkay, 1997: 3). This recommendations from this committee formed the basis of the 1990 HFE Act.

[7] As an active pro-life campaigner, David Alton was and continues to be a vocal critic of embryo research, stem cell research and cloning related developments. During the stem cell debates Lord Alton had proposed alternative legislation which would put embryonic stem cell research on hold until after a select committee had considered the implications of the research.

In pondering the relationship between opposition to the proposed amendment of the HFE Act and the perceived anti-science climate, Yvette Cooper argued that 'It would be a dreadful tragedy if the BSE crisis ... affected Members' judgement of the regulations' (HC, 17 Nov 2000: Col 1228-1229). Suggestions that arguments against SCR may be merely a reflection of a broader societal 'mood' served to discredit anti-research claims as ill-informed and fuelled by moral panic (Baroness Warnock, HL, 22 Jan 2001: Col 45).

That cloning techniques were being introduced at a time when science-society relations were under strain, led to the need for 'some serious PR damage limitation' (Sexton, 1999).[8] Carl Feldbaum, head of the Biotechnology Industry Organisation in the US, warned that to mishandle the serious ethical issue of human cloning would threaten the survival of emerging biotech companies. He went on to say that 'no current issue has more potential to undermine public confidence in the whole field of genetic and biological research than human cloning' (Anon. *Financial Times*, 1998: Jan 11). Such sentiments echoed throughout the biotechnology industry in the UK due to the increasing mobilisation of anti-research lobbyists as reported in the media. This was evidenced by the lobbying of anti-research advocate, David Alton, who, in Parliament, voiced his opposition to the Government's role in facilitating cloning research through funding biotechnological organisations (HL, 3 Sept, 1998: Col WA65).

A comparison of the anti-research tactics of the current debates with those of the 1990 embryo research debates reveals that similar strategies were employed in both contexts. Anti-cloning and SCR campaigners such as David Alton and Ann Winterton mirrored their 1990 strategies in seizing upon the ethical problems raised by embryo research. In the context of the 1990 debates, anti-research lobbyists 'decided that assisted reproduction and abortion generated the same basic moral questions about the sanctity of life, about our obligations to the unborn and about the nature of responsible parenthood' (Mulkay, 1997: 17). By the same logic, stem research was located in a lineage of issues which, according to speakers such as David Alton and Ann Winterton, firmly tied together concerns relating to abortion, assisted conception, embryo research and SCR. Similarly, during the HFE Act debates pro-embryo-research lobbyists such as the MRC were furious at what they regarded as attempts to sabotage much of its work in the area of embryo research by the pro-life alliances (Mulkay, 1997: 26).[9] The considerable amount

[8] This theme is developed in following chapters.

[9] In particular, the MRC were reacting to the success of Enoch Powell's Unborn Children (Protection) Bill in 1985. The scientific community had been shocked by the size of the vote against embryo research which saw 238 votes in favour and only 66 against. This was further compounded by an article in Nature that attempted to show how the 'enactment of

of time and research funds that had been put into developing the field of embryology, cellular development and genetic research were deemed to be under threat. Thus, in both the 1990 debates and the SCR debates, it was not only the future of the actual research that was deemed to be under threat by the growing anti-research lobby, but the integrity and future of the field of biotechnology. Whilst the pro-embryo-research lobby had been slow in mobilising itself during the 1990 debates, in the cloning debates scientists and related institutions were more actively engaged in a pro-research campaign from the outset.

Utilising tactics similar to those of the 1990 debates, both the MRC and Royal Society produced a fact sheet 'educating' the public and politicians outlining their position on SCR and cloning. Additionally, as Ann Winterton indicated in the House of Commons (17 Nov, 2000: Col 1200, 1205), representatives of science-based organisations, such as the MRC and BioIndustry Association, visited Westminster to speak to parliamentarians in an attempt to sway members who were yet to make up their minds on the issues. They also attempted to convert those who intended to vote against the amendment.

Winterton highlighted that following the publication of *The Donaldson Report*, there was a 'carefully co-ordinated propaganda campaign, with one group after another ... announcing their support for human cloning' (HC, 17 Nov 2000: Col 1200). In particular Winterton objected to the substitution of the term "cloning" with "cell nuclear replacement" by the 'fine-sounding bodies', such as those mentioned above, who supported the Donaldson reports recommendations (HC, 17 Nov 2000: Col 1200). Winterton also pointed out that parliamentarians involved in the 1990 debates 'were subjected to an almost identical campaign [and that] the present campaign is little different' (HC, 17 Nov 2000: Col 1205). The similarities between the 1990 embryo debates and the stem cell debates in terms of strategies and rhetorical manoeuvrings, is indeed corroborated by Mulkay's analysis which illustrates the utilisation of fact sheets (1997: 39) and visits to MPs outlining the medical benefits of the proposed research (1997: 40-41) during the embryo debates of the 1980s.

The 1990 HFE Act debates were a rich source of rhetoric and tactics for the stem cell debates. Put simply, those against eSCR seized upon the opportunity for redressing the embryo question and those in favour drew upon the successes of the 1990 debates by arguing that the pro-

---

Powell's Bill would prevent specific advances' (Mulkay, 1997: 27). The positive response to the Powell Bill by politicians gave the pro-research lobby the impetus to form an organised network during the 1990 embryo research debates. Up until this point the pro-research lobby had been uncoordinated compared to the energetic lobbying by anti-abortion and anti-embryo research lobbyists. The Powell Bill was eventually defeated.

embryo-research lobby had already 'won'. Integral to the success of the pro-eSCR campaign in gaining the legislative amendment, was the claim that SCR does not differ from IVF related research. Much of this argument was upheld by framing the stem cell discussions within the enclosure of debates about embryo research. That the use of the embryo for SCR would not breach the 14-day limit imposed in the 1990 Act, was an integral component of the pro-eSCR position. In debating SCR according to the framework of the 1990 HEA Act, the pro-eSCR lobby framed opposition to the proposed amendment as futile at best (afterall, the embryo debates had met their legal conclusion over a decade earlier), or insensitive at worst (for opposing therapies that could potentially cure as yet incurable illnesses and diseases). In doing so, public debates remained within well-trodden ground for the pro-eSCR lobbyists, thus foreclosing debates surrounding wider social, legal and moral concerns regarding the development of cloning techniques.

3.3 Negotiating Life: Embryogenesis in the Stem Cell Debates

In comparing analyses of the 1990 related debates with an analysis of the stem cell debates, one can determine similarities in terms of the dominance of the 'embryo question' (Franklin, 1999) and the strategic politicking of the pro and anti-embryo-research lobbies. That questions regarding the status of the embryo remained central throughout the stem cell debates clearly illustrates the sociopolitical lineage and connections between IVF and cloning related issues. The legal and moral status of the embryo, as outlined during the 1990 debates and consequently enshrined in law, are repeatedly invoked in the context of these later debates about SCR. Thus, in the following section, the relevance of the 'embryo question' to stem cell cloning debates will be explored vis-à-vis its significance in the 1990 HFE Act.

Parliamentary SCR debates were couched in terms of a proposed amendment to the HFE Act and, therefore, it is perhaps unsurprising that there was a return to many of the issues discussed prior to 1990. What is surprising is the absence of discussions about the sociocultural implications of cloning technologies for kinship relations and health inequalities. Instead, the stem cell debates are nearly always couched within the terms of ethical considerations of embryo research, such as the point at which an embryo constitutes a human being, the ethico-legal status of embryos and the medical benefits versus the exploitation of embryos for research purposes. For those arguing against embryonic eSCR, the debates provided an opportunity to restate their opposition to embryo research and related practices and to build further support. For those in favour of eSCR, the focus on scientific issues relating to embryo experimentation, arguably,

drew attention away from the more controversial issues relating to cloning through rhetorically separating scientific 'facts' from wider social and moral questions.

From the outset pro-eSCR speakers asserted that SCR does not differ from embryo research already permitted under the 1990 HFE Act. The opening speech in the Commons by Yvette Cooper, the Parliamentary under-secretary of State for Health, indicated several rhetorical strategies that were to be employed by the pro-eSCR lobby. She began by claiming that:

> Those who opposed the 1990 Act will doubtless oppose the regulations, too ... For those who support the 1990 Act and IVF treatments, there is a strong case for supporting the regulations, too (HC, 17 Nov 2000: Col 1177).

The alignment of SCR with IVF related embryo research early on in the Parliamentary debate set the tone for further discussions. Along with many other speakers, Cooper began by outlining the existing HFEA regulations, adding that the proposed regulations would introduce a sixth category of embryo research: 'increasing understanding about human disease and disorders and their treatment' (Yvette Cooper, HC, 17 Nov 2000: 1178). The new category of research, it was argued, remained within the existing constraints of the HFEA, thus preventing the use of embryos over 14 days old:

> The proposals do not alter the special status of the embryo. Embryos of up to 14 days, the current cut-off point for research, are much smaller than the head of a pin, and the 14-day point is crucial because that is the earliest point at which the first parts of what will become the central nervous system can appear. We must recognise the importance and value of the embryo. The rules governing research on the human embryo must be tightly drawn, as, thanks to the 1990 Act, they already are (Gareth R. Thomas, HC, 17 Nov 2000: Col 1197-1198).

That SCR would be subject to the HFEA's 14 day limit provided pro-eSCR speakers with a powerful rhetorical tool for claiming that the proposed amendment would not challenge the 'special status of the embryo' (Warnock, 1985) as established in the HFE Act. The arbitrary and political underpinnings of the scientific explanation and justification for the establishment of a 14 day limit in the 1990 Act received no attention in the stem cell context, instead it was accepted as a 'biological fact'.[10]

The point at which an embryo is ascribed the status of 'human being' in the HFE Act debates, was a notable point of contention. Many of those against embryo research, such as Lord Alton,

[10] See Mulkay (1994) for an excellent discussion of the coining of the term 'pre-embryo' during the 1990 debates. Also, see Pat Spallone (1989) for a brief discussion of the establishment of the 14 day limit (pp. 50- 55).

argued that human life begins at the point of fertilisation. Indeed, to use embryos in scientific experiments was deemed to be 'cannibalistic' (Alton, HL, 22 Jan 2001: Col 28). All embryos, in this view, are ascribed the status of a human being and must be treated accordingly. Indeed, Ann Winterton, a vocal anti-embryo-research protagonist, stated that she found it 'frightening' that 'we have scientists who think of these [embryos] ... simply as a source to be exploited in obtaining cells and tissue' (HL, 17 Nov 2000: Col 1204)[11].

Anti-embryo-research arguments in the stem cell debates were significantly similar to those played out within the HFE Act debates. In charting the debates and processes leading up to the 1990 Act, Mulkay (1997) describes the strategies and rhetoric mobilised by the anti-embryo-research lobby. For Mulkay, the 'recommendations of the Warnock Committee in favour of embryo research gave the anti-abortion lobby the opportunity to revitalise its activities and, perhaps, to attract additional members by focussing attention on the new topic of the destruction of 'unborn children' in scientific laboratories' (Mulkay, 1997: 18). Previous debates surrounding the 1967 Abortion Act had already provided an established set of discourses that could be transposed to future debates relating to scientific and medical uses of embryos, including the harvesting of embryonic stem cells. Thus, in mobilising the rhetoric of human rights in the context of 'science out of control', the anti-embryo-research lobby were attempting to attract supporters as well as to revitalise more general issues relating to embryo research and the beginnings of life.

The response of those in favour of embryonic SCR was to agree that whilst an embryo should have some rights, these should not be the same as those of a baby or adult human being. Human rights should develop as the embryo develops. Such arguments often drew upon the rhetoric of religion and moral philosophy. In combining scientific knowledge of embryo development and religious doctrine, speakers such as Robert Key and Dr Brand, respectively, argued that:

> I share the view of the former Archbishop of York, John Habgood, who has argued that the value that we attach to the lives of human beings -- a value that is the root of all morality -- increases as human life develops, and that we are therefore entitled, morally, to hold the life of a recently fertilised egg as less to be protected than that of a foetus at a later stage or a baby when it is born (Robert Key, HC, 17 Nov 2000: Col 1215).
>
> I do not believe that foetal cells have the same status as a unique human being. If we are going to be theological about this, I do not think that the divine soul enters when an egg is fertilised ... there is a great difference between foetal

[11] Within this part of the debate Winterton explicitly outlined her belief that embryos are not simply human cells, but are 'definitely human'.

> material before 14 days -- or indeed, a foetus of up to 22 weeks -- and a born child (Dr. Brand, HC, 17 Nov 2000: Col 1195).

One might expect the religious arguments to be mobilised by those opposing SCR, however, it was often pro-eSCR speakers that referred to such sources. Rather than simply denunciating religious arguments against embryo research, as with the 1990 debates, pro-eSCR speakers drew attention to the points of convergence of the two sides (see Mulkay, 1997: 102). They pointed to the special status of embryos beyond the 14-day period, and the protection that should be applied to foetuses and children.

Pro-eSCR lobbyists, in anticipating theological arguments, posited the anti-eSCR lobby as irrational, through parodying of the principle of ensoulment occurring at the point of fertilisation:

> Nature is profligate. We do not mourn for wasted sperm and eggs, alive though they are; nor for the three quarters of fertilised eggs that are lost before implant, half of which are genetically impaired. As the Bishop of Oxford has said, 'If every fertilised egg was indeed a soul ... then, according to these figures, three quarters of heaven would be populated by souls that lived for less than a week' (Robert Key, HC, 17 Nov 2000: Col 1215).

This science-based argument serves to normalise experimentation on embryos by claiming that scientific practice merely mirrors 'natural' processes and is therefore within the confines of acceptability. The 'natural' occurrence of miscarriage *in vivo*, is used to justify scientific uses of embryos. Baroness O'Neill argued that:

> In the normal course of events the cells of which this early stage of embryos is composed have an open future. They may become part of a human foetus and thence possibly, if all goes well, as a later stage of a human individual; or again, if much goes well, they become part of a human placenta; or they may — this is often the case — be shed. So I believe that we are not talking about a human individual or a human foetus (HL, 22 Jan 2001: Col 67).

Such arguments, in mobilising science-based discourses of human development are instrumental in constructing the use of early embryos in research as 'natural' and unproblematic. The success of the pro-eSCR lobby in the HFE Act debates was largely due to the 'transformation of participants' understanding of the experimental subject of embryo research' (Mulkay, 1997: 132). In using the term 'pre-embryo' to describe the pre-14 day old embryos, the meaning of the IVF-related research was shifted from one involving experimentation on defenceless human *beings*, to research on unformed biological *material*. Similarly, in the SCR debates, the success of the pro-eSCR lobby can be attributed to the effective negation of the 'embryos are human beings'

argument. The anti-eSCR lobby, thus, reiterated their basic moral (op)position to embryo research (which itself was taken from the anti-abortion movement (Mulkay, 1997: 132)), while the pro-eSCR lobby maintained their established science-based rhetoric that embryos under 14-days old are merely biological material; a 'small collection of cells' (Joan Ruddock, HC, 17 Nov 2000: Col 1201). Again we see the framing of the debate according to scientific and medical knowledge, re-asserting the superiority of the scientific worldview (see Irwin and Wynne, 1996).

Both sides of the SCR debates have engaged with and utilised more recent scientific research which indicate that embryonic cells have the capacity to generate life. That is, embryonic stem cells contain the information for developing into any cell type, thus procuring the conceptual shift from the whole embryo to embryonic *cells*, as 'life itself' (Keller, 1995). This shift if evident in the following quotes from anti-eSCR and pro-eSCR speakers respectively:

> It is a most wonderful being, which has the capacity to initiate, sustain, control and direct its own development. Its cells provide every different kind of cell and tissue which make up the human body — skin, nerve, muscle, bone and other organs (Ann Winterton, HC, 17 Nov 2000: Col 1203).

> [Embryonic stem cells] are pluripotent and capable of being precursors to a variety of human cell types and immortal (Lord Patel, HL, 22 Jan 2001: Col 57).

Changes in the discourses of embryos must be located in the context of changes within science, or more specifically, genetics. Recent developments in genetic research have transformed biological discourse, as Keller has argued, 'The body of modern biology... has become just another part of an informational network, now machine, now message, always ready for exchange, each for the other' (Keller, 1995: 118; also see Franklin *et al.*, 2000). This is pertinent to the SCR debates, and in particular, the success of the pro-eSCR lobby, in that this shift provides the basis for establishing embryonic SCR as benevolent. Today, the embryonic cell is increasingly replacing the whole embryo as a metonymy of life. Whereas in the HFE Act debates, the embryo was deemed to be the basic unit of life, the recent debates, whilst at once maintaining this notion, also challenged it in applying the same rhetoric to the cell.

In utilising a science-based discourse of embryonic cells rather than focussing upon social or ethical issues, the pro-eSCR speakers went on to argue that the costs of *not* doing this research are the lives of people suffering from particular diseases. Anti-eSCR speakers, on the other hand, used this to further consolidate their claims that embryos require protection:

> When the Minster tells the House of Commons that the pre-14-day-old embryo has the "power" to facilitate cures to mankind's misery, to me it simply

> underlines that, even at this early stage of development, we are not dealing with something that is inconsequential (Lord Alton, HL, 22 Jan 2001: Col 29).

This constant return to the 'embryo question' throughout the debate was, in many ways, the safety net for the pro-eSCR lobby. Comparisons to IVF-related experimentation enabled the side-stepping of broader issues - such as equal access to future health care provisions utilising stem cell techniques - and secured their success through the fall back position of the existing legislation within which the debates were contextualised:

> Some people object because we are creating embryos. That is already done and accepted (Lord Taverne, HL, 22 Jan 2001: Col 64).
>
> We are not debating today the question of whether embryo research should be allowed. Parliament decided in 1990 under the Act that such research ... could be carried out (Lord Walton, HL, 22 Jan 2001: Col 104-105).

3.4 Constructing a Demand: Curing Disease and Disability

As part of the strategy for separating reproductive and therapeutic cloning, pro-eSCR speakers repeatedly enlisted the support of groups with diseases and disabilities who are likely to be implicated in stem cell therapies. Groups such as people with Alzheimer's, Huntington's and Diabetes were constructed through emotive stories of illness and loss. Whilst there was not any consensus as to the means by which such groups could be helped, or even cured, both sides agreed upon their state of 'desperation'. The pro-eSCR lobby focussed upon the potential of SCR to cure while the anti-eSCR lobby argued that such claims were based upon false hopes and were, therefore, manipulative. In drawing upon an article in *Nature*, Mulkay (1997) shows how similar tactics were used during the 1990 debates. The article suggested that 'if a sufficiently strong link could be established between research on human embryos and increased control over genetic disability' then people's views about embryo research might be changed (Mulkay, 1997: 29). Hence, both cases focussed upon the benevolent applications for humans in aiming to transform SCR from a controversial practice into an accepted one.

The construction of a demand, or user-pull, is the focal concern of the next section where I will highlight the ways in which potential use-groups were recruited and caricatured during the Parliamentary debates. In comparing the SCR debates with the 1990 IVF and embryo research debates, I will reveal aspects of what Kirejczyk calls 'processes of entrenchment' (1995). Such processes involve struggles over definitions of the new practices according to existing linkages between 'technologies, problems, social interests, [and] arguments, socio-cultural values' (Kirejczyk, 1995: 3). Tracing the lineage of pro-eSCR discourses about SCR to pro-embryo-

research arguments associated with the 1990 debates reveals that processes of entrenchment of new technologies follow similar patterns. That is, the creation of a demand for a new technology is an essential component for gaining acceptance and consent more broadly.

The recruitment of potential user-groups was pivotal to the pro-eSCR lobby strategy and its eventual success. Parliamentarians articulated a demand for SCR by patient groups, in part, through references to letters received from individuals and organisations as well as emotive accounts of people with diseases such as Parkinson's. Speakers argued that they had a moral responsibility to these groups to allow eSCR to go ahead:

> We have a duty to society and to the sufferers of degenerative diseases (Joan Ruddock, HC, 17 Nov: Col 1211).
>
> Those who are ill and in pain cannot wait. We should not be dilatory (Robert Key, HC, 17 Nov: Col 1213).
>
> Those who are suffering can only stand by and watch us decide (Baroness Ashton, HL, 22 Jan 2001: Col 87).

In an attack on anti-eSCR lobbyists, one speaker argued that 'some of the letters that I have had opposing the proposal are somewhat lacking in compassion for their friends and neighbours' (Robert Key, HC, 17 Nov: Col 1213). Thus, pro-eSCR speakers drew upon the rhetoric of humanitarianism, arguing that to elevate the status of the embryo above that of people living with disease and disability, as the anti-eSCR lobby was deemed to do, is to devalue existing life and therefore, unethical (Gareth R. Thomas, HC, 17 Nov 2000: Col 1198; Evan Harris, HC, 17 Nov 2000: Col 1217).

The construction of potential users according to narratives of hope and fear posits them as desperate. Gareth Thomas argued that without the development of SCR, many individuals along with their families and friends will continue to live in 'hell' (Gareth Thomas, HC, 17 Nov 2000: Col 1199); many others argued that these developments are the only chance for a cure for many people. In a similar way, during the 1990 HFE Act debates, men and women experiencing fertility problems or carrying genetic disorders were also discursively constructed as desperate and according to narratives of hope and fear. In both debates the pro-embryo-research/pro-eSCR lobby effectively articulated an account of scientific progress as alleviating pain and suffering. As Franklin has argued, 'it is significant that the depiction of scientific achievements in the form of new techniques are inserted within the narrative sequence framed by the hopes and desires of infertile couples' (1997: 94). That is, science and technology are positioned as a bridge at the point when 'life's 'natural' progression' is broken off by infertility or illness. Here, as with

infertility treatment, the translation of the hopes and desires of groups with diseases and disabilities into 'desperateness' helps to naturalise stem cell cloning through embedding it within life's narrative sequence. This provides grounds for pro-eSCR speakers to position themselves as responding in both an ethical and 'scientifically sound' manner:

> If research into human in vitro fertilisation and subsequent implantation of the embryo was not permitted, hundreds of thousands of couples today would not be parents. ... Today we have the same opportunity. It is hoped that we can allow but also regulate research that has the potential to help many others — those suffering from degenerative disease, diabetes, cardiac disease and those with injuries (Lord Patel, HL, 22 Jan 2001: Col 57).
>
> This debate relates to the quality of life of sufferers from any dreadful diseases. It is not just a matter of quality of life; for some, we are talking about a question of life or death (Lord Dubs, HL, 22 Jan 2001: Col 40).
>
> Millions of people — human beings — depend on us today not to take away something which is most important to them — that is, their hope for a more dignified happier and healthier future. That hope is becoming more realistic now. ... They want to be free from the pain and suffering brought about by the diseases which have attacked them (Baroness Greengross, HL, 22 Jan 2001: Col 86).

As with other new technologies undergoing processes of 'entrenchment' (Kirejczyk, 1995), proponents of eSCR must enable (or engender) the articulation of a demand for the new technology as part of attaining cultural and political acceptability. Similar patterns of entrenchment are being following in the case of the SCR debates to those followed by HFE Act and embryo research. There is a notable similarity between the creation of a demand during the IVF and the SCR debates. Mulkay (1997) notes how during the 1990 HFE Act debates the press reported how embryo research 'would lead to more control over pain, further relief from suffering, more frequent personal fulfilment and, hence, to greater joy and happiness' (1997: 70). He then goes on to say that, 'this message of hope was regularly conveyed and reinforced by means of highly personal narratives' (Mulkay, 1997: 70). Whilst Mulkay was referring to press reportage, there was also evidence of such tactics within Parliament. Using science-based arguments, pro-eSCR speakers clearly adopted the rhetoric of hope to justify claims that IVF and related embryo research would engender 'a future in which countless people would have a realistic hope of achieving a better life with the help of the practitioners of embryo research' (Mulkay, 1997: 134).

The focus on potential cures for people was pivotal to the pro-eSCR lobby for gaining support within parliament and also for gaining support from pressure groups and organisations outwith Westminster. Potential users were constructed as not only demanding but also *needing* stem cell

therapies; without them they would continue to suffer. The characterisation of people with diseases and disabilities as desperate was a powerful rhetorical tool for the pro-eSCR lobby. The following quote demonstrates how emotive descriptions establish the notion of 'desperateness' of both those with diseases, along with their friends and families:

> [Parkinson's disease] means the end of an ability to work for someone who cannot rely on his or her body to carry out the most basic of functions – standing up straight and still, without jerking, or articulation of thoughts clearly to those he or she manages. Forced medical retirement comes next, and a gradual restriction of the social circle. Next is a declining ability to participate in conversations. There is a slow drop in the number of times the person can leave the house. There is an ever-increasing reliance and dependence on others — help with food, with getting into or out of bed, with going to the toilet, with going on holiday and for simply spreading ones wings (Gareth R. Thomas, HC, 17 Nov 2000: Col 1199).

As Franklin argued in the context of infertility, 'the cause of 'desperateness', in other words, is represented as a failure to conform to social norms' (1997: 91). In the case of infertility, it is a failure to conform to conventional ideas of adult roles through the inability to 'found a family' (Franklin, 1997: 91). The 'desperateness' of individuals with disease and disabilities is a failure to conform to conventional adult roles in terms of bodily functions, notions of dependency and ability to engage in a range of 'normal' human activities.

Understanding the ideological processes involved in constructing a demand requires us to consider the meanings of ageing, disease and disability within contemporary society. We cannot detach the negotiation of entrenchment and processes of naturalisation of stem cell techniques from meanings of health and illness. Recent research in the sociology of disability has sought to deconstruct social and cultural meanings of disability, including the conflation of disability and sickness, where the disabled body is conceived according to 'somatic and intellectual abnormality' (Paterson and Hughes, 2000; also see Turner 1995). In conflating disability and disease, the 'abnormal' body is constructed as 'an individual health problem and as an individual existential crisis which requires a charitable response' (Paterson and Hughes, 2000: 39). Disease and disability, like infertility, are stigmatised conditions, where once identified as such, 'all other identifying marks are washed away' (Pfeffer, 1987: 82). In sum, the understanding of potential user-groups according to dominant meanings of the elderly, disabled and sick reinforces and naturalises those ideas whilst simultaneously embedding stem cell techniques within established conventions of the treatment of illness.

Existing therapies and alternative research for developing treatments and cures were either ignored or mobilised in a strategic manner during the parliamentary debate. Crucial to the construction of potential user-groups as desperate was the construction of SCR as the only hope of producing therapies that would cure people. Examples of relatives who are ill or have already died were offered, providing emotive, personalised arguments intended to persuade both potential users and other parliamentarians that the 'solution provided by the new technology is a better one than the already existing options' (Kirejczyk, 1995: 2):

> I have a daughter for whom the ageing process came depressingly early, including the loss of her sight ... Research may be too late ... but for millions of mankind [sic] yet to come ... delay is simply no option (Lord Rex, HL, 22 Jan 2001: Col 78-79).
>
> When my mother died, I felt helpless. Tonight, I am at least not helpless. I could not save my mum but tonight I can try to help to save someone else's (Baroness Ashton, HL, 22 Jan 2001: Col 87).

Alternative research projects were only referred to in order to demonstrate that they were ineffectual as a cure or therapy. Therapies such as the injection of foetal brain cells to alleviate the symptoms of Huntington's and Parkinson's disease were discussed so as only to argue that such research is ethically problematic (see Lord Winston, HL, 22 Jan 2001: Col 100) and in practical terms, unfeasible (Lord Walton, HL, 22 Jan 2001: Col 105). Finally, the potential of SCR to provide cures rather than 'expensive or incomplete' pharmacological therapies or replacement surgery (Lord Rea, HL, 22 Jan 2001: Col 61), was a further argument mobilised by the pro-eSCR lobby.

Claims made by pro-eSCR speakers that stem cell therapies would empty nursing homes, thus relieving the 'burden on the health care system', framed their argument according to the responsibilities of a parliamentarian: to consider both economic and individual factors. Such arguments can also only intensify the 'somatisation of the self', where within a 'somatic society' matters of the body such as ageing, health and illness 'dominate the centre stage of political debate and political process' (Turner, 1995; 1996). Here, disease and disability are defined as individual and privatised, with matters of health and illness becoming an individual responsibility rather than a collective, social responsibility. Conversely, where we do see health and illness constructed as a public issue, as in the SCR debates, these are framed according to the terms of reference of the state and the 'medical science establishment' (Spallone, 1986: 549). That is, particular groups were defined according to processes of governance where people with various diseases where constructed as desperate and requiring intervention at the level of politics on behalf of science and medicine.

In the debates, as framed within the Parliamentary context, it has become increasingly difficult to raise broader questions about the appropriateness of cloning techniques. As Sexton has argued, 'If enough real-life stories of individual tragedies which could supposedly be averted through scientific progress can be played out one after the other ... it will seem churlish to ask questions about public health systems, inequity, distribution, exploitation, racism, eugenics and corporate control, all of which will recede safely into the background' (1999). The parliamentary debates on medical applications of cloning techniques, under the official rubric of SCR, simultaneously constructed and elicited the support of potential user-groups and sympathetic groups. In representing the proposed research according to its medical potential and foregrounding stories of suffering to demonstrate the existence of a demand, more poignant questions were successfully nullified, and indeed, rendered irrelevant within the dominant discourse.

3.5 Repositioning Infertility: From 'Desperate' to Donors

The continuation of eSCR for developing human therapies requires the co-operation of 'couples'[12] undergoing fertility treatment to donate their spare embryos for research purposes. The views of people undergoing fertility treatment, however, have been conspicuously underrepresented either in or outside of Parliament. Whilst there has been plenty of debate over the embryos in question, little attention has been paid to the sources of embryos for SCR: women undergoing IVF. Where we do see references to those people expected to donate their embryos, the discourses mobilised are revealing of social and cultural processes involving ideas of health and illness in the context of reproduction.

Explicit references to the sources of embryos were always made by pro-eSCR speakers in the Parliamentary debates. Couples undergoing fertility treatment were rhetorically recruited as allies during the debate as 'public spirited people' (Lord Walton, HL, 22 Jan 2001: Col 107) wanting to donate their spare embryos for benevolent purposes rather than have them 'destroyed'. Donating embryos for SCR, it was argued, resulted in embryos playing 'a useful role instead of

[12] In using the term 'couple' I acknowledge that fertility treatment, whilst rhetorically treating the 'couple', actually involves medical interventions on the female body to a much greater extent than the male body. 'Except for the selection and laboratory preparation of the sperm for fertilisation, the whole procedure is performed on women' (Kirejczyk, 1993: 518; also see Crowe, 1990) regardless of whether infertility is due to female or male fertility problems. Having said this, I am assuming the decision-making processes for embryo donation involves a complex negotiation between the man and woman trying to conceive, and health care professionals attached to the clinic.

vanishing into thin air' (Lord Rea, HL, 22 Jan 2001: Col 59). By this connection, those who donate their embryos would be 'contributing to the well-being of current and future generations' (Lord Rea, HL, 22 Jan 2001: Col 59).

This emotive rhetoric, as described above, is in keeping with dominant discourses of reproduction in science and medicine that couples undergoing IVF come to be familiar with. A central feature of reproductive discourses is one that entails ideas, or indeed, judgements about what constitutes a normal or an abnormal body. For those undergoing fertility treatment, issues around normality and abnormality are particularly pertinent due to their embodied negotiation of 'deficient', infertile bodies, and IVF procedures such as pre-implantation genetic diagnosis.[13] Ettorre refers to this as a 'disablist discourse' (2000). The management of bodies during fertility treatment by experts is, in part, organised according to broader social models of disability, which characterises bodies according to 'rigid definitions of health and illness' (Ettorre, 2000: 404). Given that those required to donate embryos will already be confronted with issues concerning disability through reproductive practices such as embryo selection, amniocentesis, and pre-natal screening, they are likely to have already developed an 'antipathy to what is considered to be undesirable physical, sensory or mentally-related difference or 'abnormality' in their bodies' (Ettorre, 2000: 412-413). The call to arms by pro-eSCR speakers for 'couples' to donate spare embryos to 'advance the common good' (Joan Ruddock, HC, 17 Nov 2000: Col 1210) is dependent upon already established complex social and cultural constructions of health and illness. Therefore, there is less rhetorical work to be done by the pro-eSCR lobby to encourage couples to donate their spare embryos.

In the context of embryo donation for medical research, couples are subject to discourses of responsibility. These discourses of responsibility extend beyond responsibilities to a potential child, but also include responsibilities to the science and medical profession with which they are engaged. Joan Ruddock, in her speech, recruited the support of donors in arguing that:

> More than most, they have an acute sense of what life is. They also have lengthy and close contact with medical science and an appreciation of the efforts of those who work in the service of human health and well-being (HC, 17 Nov 2000: Col 1210).

[13] Pre-implantation genetic diagnosis (PGD) is a technique used for screening embryos for genetic diseases/disorders before they are implanted into the woman's uterus. At present this technique is in its early stages of development and is only used for those at high risk (1 in 4) of passing on terminal disease to their offspring (Franklin et al., 2001). The potential for widespread use of PGD for preventing the transmission of hereditary disorders raises pertinent questions about constructions of health and illness, normal and abnormal bodies.

Here the discourse of gift exchange is mobilised, where in return for medical science helping couples to conceive a child, they have a responsibility to donate their spare embryos for SCR. There is a presumption that in participating in fertility treatment, 'couples' are in agreement with the dominant scientific model of embryos and life. This greatly simplifies the relationship between individuals undergoing fertility treatment, their embryos and the clinicians, which are complex and often contradictory. Whilst on the one hand fertility clinics trade on the construction of embryos as potential sources of life, and actively encourage the engagement of 'couples' in embryo selection and transfer processes (Goslinga-Roy, 2000). On the other hand, clinicians also 'destroy' embryos as part of the IVF process, requiring the discursive separation of 'good' embryos from 'bad' ones. This is achieved through employing developmental criteria as recorded in the lab 'exempting certain embryos from the moral and legal standards that apply to embryos as potential sources of life in the lab' (Cussins, 1996: 587).

3.6 Adult versus Embryonic Stem Cells

Debates regarding the use of embryonic versus adult stem cells[14] became a key controversy within the Parliamentary context. Concerns were articulated according to the scientific, ethical and political issues surrounding their respective advantages and disadvantages. Permeating the SCR debates were discourses of progress where SCR was intimately associated with the development of science, the economy and the human race. Whilst the pro and anti-eSCR lobbies envisaged different methods for developing stem cell therapies, in terms of the sources of cells, both sides talked uncritically of the role of SCR in furthering progress. As already indicated above, neither side considered alternative therapies, but instead focussed upon the relative costs and benefits of using embryos or adult tissue for SCR purposes. That SCR is characterised by scientific uncertainty and controversy, often meant that this particular issue was, ultimately, fought on the grounds of the 'embryo question'. In the following section I will focus upon some of the underlying assumptions that permeated questions over sources of stem cells and how the pro and anti-eSCR lobbies responded to this controversy.

Speakers advocating the use of embryos as a source of stem cells framed their arguments according to seven main, albeit overlapping, elements. Firstly, as already discussed earlier, the

[14] Embryonic stem cells are derived from embryos under fourteen days old. Stem cells are extracted from the embryo and then cultivated in the lab to produce stem cell lines. An adult stem cell is derived from tissue such as bone marrow or blood from a range of sources including umbilical cords and people of all ages. Stem cell research, regardless of the source, aims to understand the process of cell development and differentiation: the process by which cells develop into particular cell types such as brain tissue, and to develop methods to direct cells to develop into particular cell types.

use of embryos for SCR was not seen to challenge the 1990 HFE Act. That embryos would not be used beyond the established 14-day limit and the research aims are essentially therapeutic, gave credence to claims that there are no 'great new ethical issue[s] here' (Gareth R. Thomas, HC, 17 Nov 2000: Col 1197). Secondly, delaying the legislative amendment to allow embryonic SCR, it was argued, would slow down the research process and the expediency for developing stem cell therapies. Arguments for the swift development of stem cell therapies were made in conjunction with four other points: the co-development of adult and embryonic SCR, long-term research would not involve using embryos, the need for cures, and the role of SCR and biotechnology in the UK economy. Each of these points will be addressed in the following discussion.

Debates over the sources of stem cells were largely framed according to scientific and technical issues. The anti-eSCR lobby argued that adult stem cells are 'easier to manage' *in vivo* and have already been demonstrated to have health care benefits for many conditions (Ann Winterton, HC, 17 Nov 2000: Col 1204, 1205). As in the 1990 embryo research debates (see Kirejczyk 1999: 93), the parliamentary opponents of embryonic SCR switched from a rhetoric of fear to one of hope when discussing alternatives to embryonic stem cells. Speakers such as Ann Winterton, again using scientific rhetoric and evidence, argued that there is insufficient scientific evidence to support claims that embryonic SCR will 'kick start' therapeutic breakthroughs (HC, 19 Dec 2000: Col 243). Conversely, in drawing upon published scientific papers, adult stem cell sources such as umbilical cords and bone marrow were cited as having already provided some therapeutic benefits (Bill Tynan, HC, 19 Dec 2000: Col 251). Furthermore, it was argued, the 'deep divisions within the medical scientific community constitutes a strong reason for deferring making a definitive, irreversible decision today' (Baroness Cox, HL, 22 Jan 2001: Col 55).

In agreeing with the potential of adult stem cell sources, pro-eSCR speakers, however, argued that in order to ensure the development of therapies scientists should pursue both embryonic and adult SCR:

> There is not an either/or choice between adult stem cells and embryonic stem cells ... The proposals do not suggest that research into adult stem cells should be stopped. ... However, we cannot stop research in one area in the hope that another area may yield results (Dr Evan Harris, HC, 17 Nov 2000: Col 1220).
>
> It is thought that [embryonic stem cells] will increase the speed at which we obtain knowledge, [and] increase the range of diseases that we can treat and trigger the first breakthrough (Yvette Cooper, HC, 17 Nov 2000: Col 1228).

Again, arguments for the co-development of both embryonic and adult SCR were framed according to scientific and technical issues, the 'desperation' of potential user-groups and 'speed'. Scientific controversies concerning the two sources of stem cells were mobilised to justify the need to develop both techniques: if scientists are unsure as to which stem cell source will provide the breakthrough, then both avenues should be pursued. Discussions between scientists and MPs were recalled as scientific evidence within the debates. In acknowledging the importance of adult SCR, pro-eSCR speakers argued that many scientists believe that adult stem cells do not have the 'plasticity' of embryonic stem cells and, therefore, 'their use and applications are much more limited' (Lord Dubs, HL, 22 Jan 2001: Col 40).

Pro-eSCR speakers lauded the significance of embryo research in developing therapies. Claims that embryonic stem cells would speed up the research process (Gareth R. Thomas, HC, 17 Nov 2000: Col 1198) and 'trigger the first breakthrough' (Yvette Cooper, HC, 17 Nov 2000: 1228) in understanding processes of cell differentiation, were tempered with the inevitable redundancy of embryonic SCR. At the point of application adult stem cells rather than embryos, it was argued, would be used for human therapies:

> The beauty of the procedures we are discussing today is that they have the potential to make themselves redundant in the not to distant future. When the scientists have learnt enough from the cells from an embryo source, it is not beyond the bounds of possibility that they may in future be able to use cells from the adult to be treated, which will have no likelihood of rejection (Baroness Walmsley, HL, 22 Jan 2001: 102).

> The likelihood, in future, of being able to use adult stem cells or even adult cells for therapeutic purposes requires, initially, research on embryonic stem cells, cells that are pluripotent and capable of being precursors to a variety of human cell types and immortal (Lord Patel, HL, 22 Jan 2001: Col 57).

Thus positing that a decision to permit embryonic SCR is a short to mid-term practice and legislative change to permit this will simply bring forth therapeutic advances. In treating stem cell therapies as a homogeneous area, where a breakthrough in one disease such as Parkinson's signals a breakthrough writ large, is misleading. The fragmented nature of scientific research according to specialist areas, which themselves have developed according to differing historical trajectories, suggests that a unified breakthrough for all the diseases and disorders listed by scientists is a false supposition. Whilst serving as a placatory mechanism, arguments that there will be one particular point at which embryonic research is no longer needed is, therefore, overly simplistic and monolithic in its model of science.

As indicated in the introduction, the outcome of the SCR debates was deemed to be indicative of the state of science, or more specifically biotechnology, within the UK in terms of public support and science-public relations. Speakers in favour of eSCR often contextualised eSCR according to the role of biotechnology in the UK economy. In amending the HFE Act to incorporate SCR the UK economy would, in turn, be bolstered. This was further supported by the British Prime Minister at the European Biosciences Conference in November 2000, aiming to bring together the views of the biotechnology industry and parliament, crucially, during the week when SCR debates took place in the House of Commons. Blair warned against a growing 'anti-science' culture within Britain, announcing his support of eSCR and the 'revolutionary potential of biotechnology' (cited in Clark, 2000; BBC Online, Friday 17 Nov 2000). In debating the economic value of eSCR developments and the potential to develop cures for a wide range of diseases, demonstrates the successful bringing together of the interests of the biotechnology industry and government.

Claims focussing upon the economic benefits of SCR were not only made with reference to alleviating the 'burden' on the health care system through cures, but also through elevating UK scientists working in biotechnology to world leaders in their field. Indecision, it was argued, would lead to the UK losing its lead in the field of genetics (Baroness Kennedy, HL, 22 Jan 2001: Col 47; Baroness Cox, HL, 22 Jan 2001: Col 55; Lord Patel, HL, 22 Jan 2001: Col 58), with the additional problem of leading scientists leaving the UK to continue their research abroad (Lord Hunt, HL, 22 Jan 2001: Col 94). It is perhaps not insignificant that two days before the first parliamentary debate *The Times* ran a story with the headline 'Britain's biotech talent may flee 'hostile' climate', claiming that UK public attitudes to science were the worst in the world, and that research was suffering (Henderson, 15 Nov 2000). Additionally, within parliament, it was stressed by Baroness Kennedy, that the UK would 'be faced with pressure to import expensive stem cell therapies, possibly those developed in an ethically dubious and less well-regulated manner' (HL, 22 Jan 2001: Col 47). Thus, the framing of pro-amendment arguments according to the role of eSCR, and biotechnology more generally, within the UK economy, also contextualised the proposed amendment within a the broader context of a biotechnology 'race' akin to the space race.

3.7 Conclusions

Within this chapter I have shown how dominant discourses in the SCR debates, as (re)produced in Parliament, provide interesting analytical nodes from which we can observe the jostling over meanings and rhetoric by those actors and agencies involved. It is not insignificant that the UK

debates regarding the future of SCR and, by default, the development of cloning techniques have hinged upon an amendment to the 1990 HFE Act. The introduction of stem cell technologies occurred through the amendment to legislation that regulates a relatively normalised practice. This suggests that Mulkay was indeed correct in his supposition that:

> [T]here will ... be no mad rush down the slippery slope. Rather, in Britain, there will be a cautious, gradual, almost imperceptible movement into a future in which nothing will be certain except that, in the long run, the practices, expectations, values and morality associated with human reproduction will have been transformed (1997: 154).

This chapter illustrates how the rhetorical construction of SCR in the parliamentary debates slips seamlessly into existing ideas, values and practices, particularly those relating to health, illness and scientific progress. Invocations of the 1990 HFE Act have served to frame stem cell developments on relatively safe ground by focussing upon embryo research. Broader implications of SCR and cloning related developments, such as the financial cost of health care access to any therapies developed and implications upon sociocultural categories of life, death and nature were largely muted.

The range of lobbying activities and rhetorical repertoires mobilised by eSCR advocates has been central to eventual amendment to the 1990 HFE Act. As outlined in this chapter, scientists have lobbied politicians and provided 'educational' sessions in order to legitimate the use of embryos for SCR. In basing political decision making on the accounts of pro-SCR scientists and privileging 'scientific' claims about the 'embryo question', for instance, the authority of scientific knowledge is reproduced (see Gieryn, 1995: 435). Significant to this process, is the marginalisation of alternative versions of the future of SCR and cloning-related developments. Whilst lip-service was paid to controversies surrounding SCR, ultimately, the grounds on which the debate took place were achieved through what Gieryn calls 'boundary-work' (1995).[15]

Whilst this chapter has focussed upon the rhetorical manoeuvrings relating to the SCR debates within Parliament, the following chapters will explicate the range of meanings attached to SCR and cloning and its related practices. Building upon some of the analytical themes introduced in this chapter, I will move on to explore the accounts of scientists working in the field of SCR and cloning, and relevant social groups. Firstly, in chapter 4, I will outline the theoretical frameworks and conceptual tools that have informed my analysis of the SCR and cloning debates and analysis of interview transcripts with scientists and other relevant social groups. Secondly, in

[15] The concept of boundary-work will be further explored in Chapter 5 where I will examine how scientists construct rhetorical boundaries such as that between science and society.

chapter 5 I present scientists' discourses – revealing the rhetorical devices and repertoires mobilised by scientists when accounting for their work in the field of eSCR. After outlining the centrality of pro-eSCR scientists' constructions of this area in this chapter, it is then important to develop a deeper understanding of those accounts that have underpinned the parliamentary debates. Thirdly, in chapters 6 and 7, I go on to analyse the issues as defined by other relevant social groups – which in this research are the patient groups listed in chapter 2. The inclusion of different publics' understanding of the issues surrounding SCR and cloning-related developments is an important step in revealing the omissions, the gaps and the silences in 'dominant' accounts of this controversial area. In moving away from debates framed according to 'operational categories of government' (Irwin, 2001: 9), I am thus able to explore multiple constructions of SCR and cloning as they relate to various peoples' everyday experiences and social location.

CHAPTER IV

Understanding Transformations in Science-Public Relations: The Approaches of Beck and cPUS

4.1 Introduction: Troubled Science-Public Relations?

As already noted in the previous chapter, the SCR and human cloning debates have taken place within a broader context of mounting concern in the scientific establishment about strained science-public relations. Scientists and social scientists alike have perceived an increasing erosion to the privileged status of science in society, and turned their attention to what has been termed, the current 'crisis of legitimacy'. As Mike Michael has argued:

> Gone are the days when members of the public gazed, wide-eyed with credulity, at the great men of science; lost forever is the era when the layperson listened in silent admiration and humble wonder to announcements of the latest scientific discovery; never again shall we hear the awed gasps of the masses as the covers are removed from the newest shiny technological artefact (1996a: 105).

This rather dramatic quote suggests a growing public disenchantment towards the scientific enterprise – especially in connection with 'exotic' technologies (Michael, 2000) such as those associated with the new genetics. That the traditional standing of science and scientific expertise is increasingly under threat is exemplified in the growing number of organisations and interest groups contributing to recent controversies, creating new and alternative forms of expertise. For example, organisations such as the *Genetic Engineering Network*,[1] *GeneWatch UK*,[2] and *The Cornerhouse*,[3] exemplify the growth of alternative sources of 'expert' knowledge. Such organisations provide 'alternative' accounts of genetic developments, introducing issues such as economic interests, biodiversity and different images of the future direction of this area of research. And, whilst it may be historically inaccurate to claim that challenges to science are an entirely new phenomena (see for example Turney, 1998; Collins and Evans, 2002: 275), there are

[1] The *Genetic Engineering Network* are opposed to genetic technologies and the corporate interests in this area. See http://www.geneticsaction.org.uk

[2] *GeneWatch UK* describes itself as a not-for-profit public interest group, that aims to raise awareness of the ethical aspects of genetic technologies and applications of genetic knowledge. See http://www.genewatch.org

[3] *The Cornerhouse* is an NGO that aims to support democratic and community movements on a range of issues, including genetics, SCR and cloning. See http://www.thecornerhouse.org.uk

indications that responses to this problem by both publics and experts have altered as challenges become 'normal rather than exceptional' (Van Loon, 2002: 25).

The problem of legitimacy and scientific authority is acutely apparent in the SCR and cloning debates, to which those scientists involved are keenly sensitised. Located at the interface between scientists and publics, the public debates on SCR and cloning can be seen as 'points of connection' where trust and authority can be built up and maintained or challenged and undermined (see Giddens, 1990: 88). As already noted in Chapter 3, some scientists have regarded the public debates on SCR and cloning as a key site for redressing science-public relations, where the outcome could make or break public confidence not only in SCR but in the whole field of genetics and biotechnology (see section 3.2). At stake for many scientists engaged in the debates is the constitution of expertise and expert identity vis-à-vis non-expertise and lay identity. This is further complicated by the range of competing constructions of SCR and cloning offered by different scientists and other 'experts' (e.g., politicians), where one version is yet to reach stabilisation (see Pinch and Bijker, 1984). To this extent, the public SCR and cloning debates are sites were particular definitions of expertise are being constituted in ways that include (and, therefore, benefit) some positions while excluding others.

Both scientists and social scientists alike have acknowledged that relations between science and the public are undergoing processes of transformation that have broader implications for expertise in general. In the new knowledge-based market, scientists' expertise is increasingly located alongside other forms of expertise that have emerged, such as through patient group organisations and other interest groups (see Novas and Rose, 2000; also, McNeil, 1998). The reconfiguration of power relations between experts and the public illustrates that the interrelations between science and the public are not static and fixed, but are dynamically negotiated and constructed through ongoing associations that are in need of 'constant repair and reproduction' (Michael, 1996a: 129). Rather like the concept of hegemony, science-public relations do not take place on a level playing field and yet the privileged status of scientific expertise is never 'won' or achieved – it is always in a state of becoming.

The SCR and cloning debates, then, are a compelling site for exploring scientists' discursive mechanisms and stratagems for dealing with waning public trust in science and its institutions, as well as gaining insights into the 'internal politics' of controversies about science. If scientist working on SCR do indeed feel that their authority is increasingly undermined, then what interpretive practices are employed when (re)constituting expertise? Do scientists continue to appeal to binaries between expert/public, inside/outside, science/social and if so, are they

renegotiated in new ways? In posing this, it is also important to explore how 'non-experts' constitute SCR and cloning and the range of discursive repertoires mobilised. To this extent, we must ask how publics conceive of the relationship between scientists and publics? What are the points of convergence and divergence between scientists' and publics (in this case, patient support groups) in their accounts of SCR and cloning?

The aim of this chapter is to introduce the theoretical approaches and conceptual tools that underpin the following three chapters. In exploring the multiple ways in which SCR and cloning are constructed, as well as sensitising my analysis to processes of inclusion and exclusion, I have turned to two related 'meta-theories' within social science: the work of Ulrich Beck and the sub-discipline within STS referred to as critical approaches to the public understanding of science (cPUS). These approaches have informed my understanding and analysis of the intersection of a number of core issues at stake in the SCR and cloning debates: expertise, risk, (un)certainty and (mis)trust. In particular, I argue that the theoretical, conceptual and methodological insights of Beck and cPUS provide a critical backdrop to the SCR and cloning debates for developing incisive analyses of the nature and extent of transformations in science-society relations.

4.2 The Paradoxes of Reflexive Modernity: Risk and Uncertainty in Expert Systems

The theoretical underpinnings of this chapter can be traced back to Ulrich Beck's 'Risk Society' thesis (1992). In this seminal work, Beck provides an analysis of transformations that are occurring within contemporary Western societies that continues to contribute to a range of debates, encompassing a number of substantive areas including political life, interpersonal relationships, employment and, most importantly for my own purposes, developments in science and technology. By analysing these areas of society and social life, Beck illuminates transformations that are taking place within modernity, captured in his theoretical concept of 'reflexive modernity'.[4] Processes of reflexive modernisation relate to an epochal shift from modernity – as associated with industrial society and the project of enlightenment – to a new reflexive modernity (Beck, 1992). The concept of reflexive modernity involves the idea that modernity's institutions have become 'self-refuting' where the project of 'modernity' is confronted by itself and begins, in turn, to transform its own principles and institutions (Beck, Bonss and Lau, 2003). As the logical development of the project of modernity, processes of

[4] The notion of reflexive modernisation has been co-developed but in different ways by Ulrich Beck, Anthony Giddens and Scott Lash during the later 1980s to early 1990s (see Beck, 1994: n1).

reflexive modernisation characterise a distinct phase *within* modernity (Beck does not adopt the term *post*modernity), which Beck, Bonss and Lau have recently referred to as '*the modernization of modern society*' (2003: 1, original emphasis).[5] Inherent in this mode of analysis is an attempt to capture the 'delicate balancing between the contradictions of continuity and rupture within modernity' (Beck, 1992: 9). Hence, Beck puts forward a non-linear model of change, characterised by tensions and contradictions where our modes of thought and action are caught between the past, present and future; tradition and reflexivity (Beck, 1992: 20).

Rather than continuing with a description of Beck's thesis (since a thorough exegesis of his work is a task that would be too wide-ranging and complex to be adequately conducted in this discussion), I will provide a brief overview of Beck's account of the risk society. For Beck, risk is a consequence of processes of modernisation and, therefore, intimately linked to reflexivity. For these reasons, I will focus upon the implications of risk for transforming our notions of expertise – and specifically scientific expertise – in contemporary western societies. In doing so, I will explicate Beck's understanding of the contemporary condition as one characterised by the dissolution of certainties and where 'natural-scientific categories' no longer enjoy a monopoly on risk calculation and definition (see Beck 1992; 1995).

Central to Beck's analysis of the paradoxical processes of reflexive modernisation, is an account of the transformative consequences of risks which have proliferated within (first) modernity. According to Beck, with the 'exponentially growing productive forces in the modernization process' there has been a qualitative change in social order from the creation and distribution of 'goods' (such as wealth creation) to one of flows of 'goods' *and* 'bads' (1992: 19; see also Lupton, 1999; Van Loon, 2002). This shift – which is intimately linked to the production and dissemination of knowledge (e.g. the mass media, new communications technologies, and an improvement in educational standards and literacy levels) – locates science and technology as central to the processes of reflexive modernisation. For instance, developments in science and technology have themselves created 'hazardous side effects', such as environmental threats and other threats to human life (Beck, 1992). These unintended and unforeseen side effects of modernisation have created an excess of risks that have come to dominate both public and private arenas, thus generating a 'risk consciousness' where individuals are increasingly preoccupied with risks (Beck, 1992).

[5] Distinctions between these two phases are also referred to as first and second modernity or simple and reflexive modernity (Beck, Bonss and Lau, 2003; Lash, 2003). More recently, the latter stage has been identified as re-modernization (Beck, Bonss and Lau, 2003; Latour, 2003).

Whilst recognising that risks – in terms of threats to lives – have existed within previous epochs, Beck argues that there are a number of features that are specific to contemporary risks. Significantly, risks are 'open-ended events, rather than events that have a foreseeable end' (Lupton, 1999: 62). To this extent, risks cannot be predicted, controlled or avoided and are no longer delimited in time or space. A further feature of contemporary risks, such as food toxins or radiation, is that they are largely imperceptible to the human senses and, therefore, transcend traditional social categories, such as class, according to which risks had previously been distributed in western societies. As Adam and Van Loon argued, 'the essence of risk is not that it *is* happening, but that it *might be* happening' (2000: 2, original emphasis). And it is in this context, that 'risks exist in scientific knowledge rather than in everyday experience' (Lupton, 1999: 64).

The complexity and open-endedness of contemporary risks, has resulted in traditional means of scientific risk assessment (that are based upon calculation, management and avoidance) losing both their efficacy and authority. According to Beck, 'techno-scientific rationality' has failed because expert systems relating to science and technology continue to be grounded in the institutional and methodological approaches of modern science (e.g. non-reflexive) (1992: 59). Experts' use of the language of certainty and empirical accuracy in relation to risk assessment, exemplifies for Beck, how the sciences are '*entirely incapable* of reacting adequately to civilizational risks' (1992: 59, original emphasis). The industry of 'risk assessment' is a modern attempt to deal with risks inherent reflexive modernity and is, therefore, destined to fail. As Adam and Van Loon have argued, non-reflexive responses to risks 'belong to the realm of rational action and scientific certainty, a realm of clear distinctions between safety and danger, truth and falsity, past and future' (2000: 7). In continuing to reproduce non-reflexive accounts of risks, modern expert institutions undermine themselves and invite public scepticism through their failure 'to provide ... security whilst pretending to do so' (Wynne, 1996: 56).

That risks are both more messy and more insidious has resulted in high degrees of public ambivalence towards 'expert systems' where the cognitive authority of expert systems no longer goes unchallenged.[6] Challenges to scientists' authority by public groups have been brought

[6] I have taken 'expert systems' as referring not simply to individual experts, but to a complex range of social and cultural networks that contribute to the construction and authorisation of expertise, including institutional mechanisms, professional practices and knowledge production (see Giddens 1990, 1991; Lash, 2000; Van Loon: 2002). It is important to note that the concept of 'expert systems' vis-à-vis reflexive modernity has been separately developed by Giddens and Beck, albeit with different meanings. Giddens focuses upon how trust in expert systems help us to achieve 'ontological security' and, therefore, distrust in expert systems engenders 'ontological insecurity'. It is the latter that is characteristic of

about, according to Beck, as a result of a public knowledge and awareness of contemporary risks which coincides with the demystification of the sciences (1992: 59). There has been, he argues, a growing consciousness of the involvement of science and technology in the origin and growth of risks, as well as their failure to assess or contain them. Specific to the public perception of risks in the contemporary era is the development of a greater 'sensitivity towards the unintended consequences of our actions which includes an awareness of an 'open' rest-category, that is, the inevitability of other unintended consequences we do not and cannot yet know' (Adam and Van Loon, 2000: 13; see also Wynne, 2002: 469). The very nature of contemporary risks, as ambiguous and open-ended, renders them open to social definition and construction and, therefore, inherently political (see Beck, 1992: 23; Adam and Van Loon, 202: 4). According to Beck, the ambiguity of our knowledge of the causes and potential solutions to risks, marks the 'return of uncertainty to society ... [where] ... no one ... or everyone is an expert' (1994: 8-9). That is, if cognitive authority no longer resides within expert systems, then expertise becomes decentralised and pluralized. Or to take his argument one step further, expertise, in the conventional sense, no longer exists at all but instead is challenged by new and alternative forms of 'expertise' which requires the researcher to develop new analytical and conceptual tools.

In this respect, developments in science and technology have opened up new spaces for critical engagement with those very mechanisms that have produced them. Risk conflicts are no longer confined to the realm of 'experts' within science and technology, but also include a range of public groups. It is here that Beck has identified the emergence of 'sub-politics', where risks have 'activated' citizens into alternative initiative groups and political movements, giving rise to competing rationalities which reflect a range of interests (Beck, 1992: 195). These sub-political activities have challenged the cognitive authority of science and technology, created new forms of expertise and, therefore, opened up the political sphere (Beck, 1992).

What Beck's theory of risk and reflexive modernisation offers us, then, is a critical approach for understanding the current transformations that are taking place within western societies. This approach, in particular, offers a dynamic model of social change as brought about by the pervasive sense of risk. The production of an excess of 'bads' by modernity's institutions of science and technology are beginning to undermine their own promises and programmes (Wynne, 1996). As traditional modes of risk assessment and avoidance fail, public trust in those

---

reflexive modernity which has occurred as a result of a shift in trust relations which are now founded not on face-to-face interaction, but through relations with abstract systems (see for example, Giddens, 1990: chapter 3; Lash, 1994: 116-119). In sharp contrast, for Beck 'reflexivity is based not in trust but in distrust in expert-systems' (cited in Lash, 1994: 116). Thus, expert systems are an obstacle to the achievement of security and by extension, to the radical potential of reflexivity.

expert systems wanes, and uncertainty and ambivalence increase. In turn, new political constellations emerge which offer alternative interpretations of risks, thus contributing to the erosion of the legitimacy of science and technology as *the* authorities on risk definition. However, this is not to suggest that the project of Enlightenment and progress as pursued via science and technology has been abandoned – Beck does not advocate an anti-science position. Instead, as Furedi argues, challenges to expert systems mark one of the ironies of our times: 'while society is more dependent on science and technology than ever before, it is also more suspicious of their consequences' (1997: 131). This returns us to the paradoxes of the processes of reflexive modernisation, where change is characterised as non-linear and our modes of thought and action are caught between tradition and reflexivity.

It is within this context of growing overt, public ambivalence towards expert scientific expertise that scientists and related experts are operating. And as Van Loon has argued in his analysis of the risk society, whilst it is important to note that challenges to the cognitive authority of science and technology do not constitute a new phenomena, 'such challenges have become normal rather than exceptional' (2002: 25).[7] However, again we should note that reflexive *and* traditional forms co-exist. This is to say that whilst the authority of expert systems are currently being *challenged*, their power and influence are far from usurped. In terms of defining, constructing and legitimating risks, experts such as scientists and politicians remain in key social positions as mediators of knowledge (see Adam and Van Loon, 2002: 4; Beck, 1992: 23). Hence, with the potential dissolution of old certainties and increasing mistrust and scepticism of expert systems, conflicts over interpretations of risk become central (see also Irwin, 1995: 44).

4.3 Reflexivity in Traditional Models of PUS: The Shoring Up of Authority or Public Inclusion?

The development of Beck's *Risk Society* thesis has converged with what has since come to be known as critical approaches to the public understanding of science (cPUS) (see, for example, Irwin and Wynne, 1996a).[8] During the 1980s, writers such as Brian Wynne had also turned their attention to issues of risk, credibility and expertise vis-à-vis science-public relations in contemporary society. Whilst Beck and cPUS initially developed separately, the approach of cPUS has since gone on to critically engage with and advance Beck's theory of risk and our

[7] See Turney's *Frankenstein's Footsteps* (1998) for an historically informed discussion of the various ways in which science, technology and medical interventions into the human body have been met by public resistance.

[8] A point of clarification: I will refer to critical approaches to the public understanding as 'cPUS', and traditional, institutionalised models of science-public relations as 'PUS'. The differences between these will be apparent as the discussion develops.

understanding of processes of reflexive modernisation as they relate to expert systems in science and technology (see Wynne, 1996). As this sub-field of science and technology studies has developed, cPUS has become heterogeneous in its theoretical and methodological approaches.[9] Some of the most prominent work carried out in the sub-discipline of cPUS has come from a number of case studies that have illuminated upon the political nature of risks by charting the ways in which experts and the public interact. In taking a range of issues and debates as their subject matter – including radioactive fall-out (Wynne, 1992; Public Understanding of Science, 1992), agricultural herbicides (Irwin, 1995), BSE/v-CJD (Van Loon, 2002), xenotransplantation (Brown and Michael, 2002), and the new genetics (Kerr, Cunningham-Burley and Amos, 1997, 1998a, 1998b; Kerr and Cunningham-Burley, 1999; Cunningham-Burley and Kerr, 1999) – these studies have contributed to theories of reflexive modernisation and risk society. Spanning across disciplines such as anthropology, science and technology studies, public health sciences and sociology, cPUS approaches have sought to problematise how the categories of 'expert', 'public', and 'knowledge' are defined and bounded by a range of different actors (Wynne, 1996: 46). Such perspectives aim to capture the social and cultural dimensions of science-public/expert-lay relations and, in turn, extend our understanding of reflexive processes, theories of reflexive modernisation and risk in contemporary society.

In this section, I will introduce a number of key arguments put forward by cPUS writers, especially as they relate to some of the ways in which expert systems have grappled with the consequences of reflexive processes within society. In particular, I will focus upon institutionalised PUS initiatives that have attempted to redress science's crisis of legitimacy, and consider to what extent these reflect reflexive or traditional conceptions of risk and expertise.

Although scientists remain in key social positions, the problems generated by uncertainty, trust and legitimacy have not gone unnoticed, but have taken a prominent place in debates around science and technology. As Irwin has noted, since the beginnings of the Industrial Revolution, scientists have recognised that in order to promote and maintain public acquiescence towards science, they must play an explicit political role in the new world order (1995: 12; see also Yearley, 2000). Irwin argues that from the establishment of the Mechanics Institute in the early nineteenth century, through to the *Royal Society's* 'Public Understanding of Science' report in 1985, certain assumptions about science and the public have dominated these activities. In particular, 'the public' are conceptualised as 'uneducated' and 'ignorant' in matters relating to

[9] Whilst cPUS research tends to adopt qualitative research methods, a team of researchers across Europe have conducted research into the public understanding of biotechnology using a more sophisticated approach to quantitative research methods (see Durant, Bauer and Gaskell, 1998; Gaskell and Bauer, 2001; Bauer and Gaskell, 2002).

science and technology, with the assumption being that science is central to the future betterment of individuals and society (Irwin, 1995: 14). Greater understanding of science, it was believed, would lead to greater acceptance and support for science and technology. Hence, a fundamental issue underlying scientists' concerns about public understanding of science was to generate legitimacy for scientific expertise and to reassert scientists as mediators, *par excellence*, of the natural world.

Scientists' characterisation of public mistrust, scepticism and insecurity as 'ignorance' has given rise to models of science communication that aims to educate the public in matters of science and technology. Since 'understanding' of science is equated with scientific knowledge public scepticism is renounced as *mis*understanding – 'a shortfall of the scientific facts' (Thomas, 1997: 163; see also Beck, 1992: 58). Such a view closely resembles Beck's point that the sciences continue to reproduce 'techno-scientific rationality' in their understanding of science, risks and the public. Beck's scathing attack on dominant models of PUS are evident in the following quote:

> The technical risk experts *are mistaken* in the empirical accuracy of their implicit value premises, specifically in their assumptions of what appears acceptable to the population. The talk of a 'false, irrational' perception of risk in the population, however, crowns this mistake; the scientists withdraw their *borrowed* notions of cultural acceptance from empirical criticism, elevate their views of other people's notions to a dogma and mount this shaky throne to serve as judges of the 'irrationality' of the population, whose ideas they ought to ascertain and make the foundation of their work (1992: 58).

Hence, this model of science-public relations characterises 'the public' as a homogeneous mass and rather than distinguishing between different publics and their views, science/society, expert/lay dichotomies are reproduced. This approach for redressing science-public relations has been termed the 'cognitive deficit model', or simply, the 'deficit model' by cPUS advocates.

It is this notion of public ignorance and misunderstanding – as encapsulated in the deficit model – that those working in the area of cPUS have taken issue with and in doing so have converged with Beck. Within science and technology studies, the work of Brian Wynne has been influential in the establishment of cPUS (see Wynne, 1988, 1992, 1995; Irwin and Wynne 1996a). According to Wynne, we need to problematise what is meant by both 'science' and 'understanding', which, in turn, automatically problematises the 'public' (1995). Although Beck does acknowledge non-reflexive accounts within the sciences to public perspectives (1992: 58), he does not fully attend to the problem of *how* the category of 'expert' is defined and mobilised in risk debates (Wynne, 1996). In addition to this, Beck's work is not based upon empirical

research. One focus of cPUS, on the other hand, has been to investigate how science is represented and constructed within dominant models of PUS through empirical analyses.

The implicit understanding of scientific knowledge, practices and institutions as 'closed' within dominant models of PUS has been criticised by a number of writers within cPUS. For example, Wynne has argued that there is a tendency to present science 'as if it were a value free and neutral activity ... [which] ... *illuminates* and *assists*' (Irwin and Wynne, 1996b: 6, original emphasis). Rather than attending to the inevitable indeterminacies and uncertainties within science, PUS models instead, construct science as proceeding according to 'mechanical, rule-following behaviour' (Wynne, 1988: 148) by 'playing up the methodological character of their knowledge' (Yearley, 2000: 225; see also Beck, 1992: 58-59). This uncritical conception of science and scientific knowledge closes off reflexive debates about the 'epistemic commitment, social purposes, institutional structures, [and] intellectual boundaries' within science (Irwin and Wynne, 1996b: 4). To this extent, then, cPUS is critical of the ways in which traditional models of PUS engender a recourse to techno-scientific rationality and an uncritical conception of science, scientific knowledge and the public.

In keeping with Beck's ideas on reflexive modernisation, Wynne has argued that the dominant institutionalised model of PUS – where science continues to be conceived according to a rationalist temper – may 'undermine itself by the nonreflexivity of science about its own constructions of "the public" and the institutional factors that give rise to these constructions' (Wynne, 1995: 365). Responses to public mistrust that reproduce modes of thought and action associated with first modernity are counterproductive 'because science cannot be automatic and method-based, free of trust and judgement' (Yearley, 2000: 226; see also Wynne, 1992). Therefore, to present science as the *only* valid explanatory regime, excludes alternative voices and in turn, further generates public ambivalence and dissent. The point to note here is the convergence of cPUS and Beck in their view that non-reflexive models of PUS can, potentially, engender further public reflexivity.

The dominant PUS view that public mistrust can be corrected by educational means, firmly places responsibility at the feet of the public and leaves science unproblematised. Instead of applying the deficit model to the public understanding of science, many cPUS studies have shown that there is no significant correlation between knowledge levels and support for science (see Thomas, 1997: 169; Collins, 1987). Whilst recognising that scientists have some responsibility as communicators, the starting point for critical approaches is a recognition that individuals are not simply information repositories. Public perceptions of science and

technology are, instead, understood as based upon the perceived credibility and trustworthiness of expert systems along with the individuals and institutions that constitute them. Public scepticism towards science and scientists is contextualised according to the social framework within which science-public relations exist, which Wynne calls the 'social package' (1992: 282). This refers to the material social relationships, interactions and interests according to which people experience, define and judge risks and scientific information. For instance, in the case of controversial developments, publics are confronted with conflicting arguments and expertises (see Collins, 1987: 691) and to this extent, public 'understandings' cannot be reached simply through scientific 'facts' but must always involve non-scientific and non-technical judgements. Hence, public responses to and experiences of science, and associated risk perceptions, are always the result of active engagement and interaction with science and scientific knowledge as embedded in social relations, even when the public response is 'ignorance' (see Michael, 1996b; Wynne, 1995). In short, public understandings of science and risk must always take into account existing social relations and social identities.

Critical approaches to PUS, firstly, take into consideration the plurality and diversity of public groups vis-à-vis public perceptions of science. Individuals cannot be reduced to any single or fixed social identity, but inhabit a range of complex and often contradictory identities that evolve and shift over time. Secondly, the social context within which publics encounter science is analytically significant. For example, the historical context, previous knowledge and experience of expert systems which impact upon whether they trust or find scientists claims credible. Closely related to this is people's relationship to power, resources to use 'scientific' knowledge and its relevance to their existing experiential knowledge, which Wynne refers to as the 'tacit models of social agency underlying encounters between science and public groups' (Wynne, 1995: 363; see also Wynne, 1992). By this connection, public mistrust, ambivalence or dissent towards techno-scientific rationality – translated as ignorance according to the dominant model – should, in fact, be understood as the effects of misrecognition: 'they do not recognize it, or identify with it' (Wynne, 1992: 282). Hence, critical approaches to PUS have illustrated how science-public relations are grounded in social relationships between the different actors in any instance.[10]

[10] It is important to note that these critical interventions into science-public relations and decision-making processes are themselves a contribution to reflexive modernity. By deconstructing dominant models and discourses of PUS, a number of social scientists have engaged with and articulated the voices and opinions of a range of public groups in order to gain public inclusion within policy-making and decision-making processes and also to change the basis upon which these are made (see for instance, Irwin, 2001). The active engagement of social scientists as intermediaries between scientists, government and the wider public, constitutes cPUS researchers as spokespeople within debates, or what Irwin

Increasingly, the 'social package' through which publics formulate their views, includes factors relating to the changing nature of scientific institutions and the political economy of science. The changing role of science itself, in terms of its function within policy-making and regulatory processes, along with the 'growing commercialisation of research' (Yearley, 2000: 232) mean that science can no longer be regarded as a purely disinterested intellectual pursuit. In this context, issues of public understanding of science and related risks are not limited to the trust and credibility that they are willing to invest in scientific spokespersons or institutions, but also extend to 'experts' that traditionally fall outwith the field of science, such as legal systems, pharmaceutical companies, religious groups, politicians and financial investors. Again, this returns us to the inherent contradictions of the dominant model of PUS that have been brought about by the modernisation of science and its institutions. Transformations in the features of the scientific enterprise, where science can no longer be compellingly separated from social or political spheres, have contributed to reflexive processes.

4.4 Towards a Reflexive Model of PUS?

What I have attempted to address thus far, is to present the convergences between Beck's theory of reflexive modernisation and cPUS. More specifically, these two complimentary and overlapping approaches offer an analytical framework for exploring the dynamics of science-public relations and for creating critical interventions into dominant models of PUS. In engaging with debates on reflexive modernisation, cPUS approaches have, to some degree, 'tested' how much both expert systems and publics are becoming reflexive, and in doing so have begun to map out the complex forces that are contributing to current transformations. As a next step, this section will consider the co-evolution of PUS and cPUS approaches to the 'crisis of legitimacy' in science's expert systems. In particular, I will critically consider the apparent shift towards reflexive models of PUS within science through the lens of critical approaches to science-public relations.

Brown and Michael have, like Beck, argued that the current crisis in legitimacy extends beyond the realms of science to other forms of expert systems (2002). Across a number of realms – including finance, commerce and politics – issues of trust, credibility and legitimacy have become central to institutional decision-making processes. In seeking to redress the lack of trust

---

refers to as 'experts of community' (2001: 15). In accordance with Beck's terms, the implicit political agenda that underpins cPUS has contributed to the emergence of 'sub-political' activity (Beck, 1992).

in expert systems, many institutions and organisations have adopted the strategy of 'transparency'. That is, institutions and organisations are increasingly disclosing information regarding decision-making processes, working practices and financial documents that have previously remained private. In addition to this, members of the public are invited to attend meetings and respond to policy documents in order to 'persuade us that they have engaged with the debate and have listened to and digested other points of view' (Brown and Michael, 2002: 260). For instance, during the decision-making stages of policy creation, bodies such as the HFEA release questionnaires that aim to encourage the public to respond to and engage with the issues at hand. Similarly, the Human Genetics Commission have addressed the issue of trust by opening their meetings to the public (see www.hgc.gov.uk). Hence, these practices illustrate how transparency is being performed within expert systems in order to improve the crisis of legitimacy and trust.

This shift towards inclusion and openness is mirrored within recent reports and initiatives that fall under the general rubric of the 'public understanding of science'. In contrast to the model of PUS associated with the Royal Society's 1985 report (as discussed above), there has, since the late 1990's, been a shift in rhetoric that focuses on 'dialogue' and 'engagement'.[11] Undoubtedly in response to pressures and critical spaces opened up by critical approaches to PUS, the sociology of science and other collective actors such as environmental groups, new forms of argumentation have been translated and incorporated into policy-making processes (see Irwin, 2001; Wynne, 2002; Beck, Bonss and Lau, 2003). As Irwin has argued, 'for anyone who has followed science and technology policy debates in the UK over the last few decades, the congruence of official statements and social scientific findings seems remarkable indeed' (2001: 3). For instance, in February 2000 the House of Lords Select Committee on Science and Technology published its report, *Science and Society*, outlining concerns of a lack of public confidence in science. Focussing on issues of trust, the inherent uncertainty and complexity of science and public ambivalence, the report calls for changes to the culture of policy-making in order to ensure that openness and transparency within science become the norm. In the context of this 'new mood for dialogue' the *Science and Society* report encourages science and its institutions to adopt innovative methods for integrating public views into science-based policy-making. Following on from this the *Royal Society* established its own *Science in Society* programme which aims to 'earn public confidence' by developing 'innovative, widespread and effective ways of communicating with the public' and to 'ensure that the voice of the public is heard when

[11] For instance, the *Wellcome Trust* has recently established a new grants scheme, 'Engaging Science', allocating £3 million per year for schemes and projects which seek to develop and improve public involvement in biomedical science (www.wellcome.ac.uk/engagingscience).

shaping and discussing science policy'.[12] Other illustrative evidence can be found in the increasing number of public forums for scientists to present and discuss their work which include conferences specifically organised to address the 'public understanding of science'.[13]

During the period when policy makers were highlighting the need to move beyond the deficit model there were a number of high profile controversies, including BSE/v-CJD, Foot and Mouth disease, GM crops, MMR as well as human and animal cloning. In these cases, public scepticism towards scientific authority adds further weight to 'calls for a recognition of the fundamental nature of scientific uncertainty, [and] of the significance of public trust and confidence' (Irwin, 2001: 3). In this current context,

> institutional bodies of government and policy have been forced to experiment with increased public participation in various arenas of expert decision over risks and technology regulation, in response to waning public trust in their processes and outcomes (Wynne, 2002: 465).

In analysing these new forms of consultation and decision-making practices, cPUS research has revealed two central moves: the performance of transparency (Brown and Michael, 2002) and the translation of a plurality of public meanings into scientific discourses (Wynne, 2002). This recent shift in rhetoric and practice – what Brown and Michael have called the 'transparency turn' – is 'part of a powerful repertoire of signification on which the authority of both politics and science is itself based' (Brown and Michael, 2002: 263). Put simply, if decision and policy-making processes in science and technology are made to appear open and transparent, then science and scientists appear to be accountable and, in turn, scientific authority is reasserted. By this connection, transparency becomes the solution for problematic science-public relations.

The logic of attaining transparency, according to Brown and Michael, involves the assumption that 'there is simply nothing more to know and that all relevant information is available' (2002: 263). However, in the context of increasing ambivalence and mistrust towards expert systems 'the logical grounds for such scepticism is that transparency is always compromised, and is

[12] Additionally, the *Royal Society*, in response to its 'Public Understanding of Science' report in 1985, continues to co-fund the *Committee on the Public Understanding of Science* with the *Office of Science and Technology* (www.copus.org.uk). Again, the 'public' agenda of this committee has shifted from education and ignorance to engagement and dialogue.

[13] For instance, the *European Molecular Biology Organisation* and the *European Molecular Biology Laboratory* held a joint conference on Science and Society in November 2000, entitled 'Developing A Dialogue'. This was attended by scientists as well as social scientists and representatives from lobbying organisations and interest groups. We have also witnessed the emergence of organisations such as *Café Scientifique* and *Sci-Bar* within a number of UK cities, which are public forums for scientists and publics to discuss new developments in science.

therefore *de jure* unattainable' (Brown and Michael, 2002: 260). In other words, for transparency to be convincing, the institutions or individuals performing transparency must *already* be trusted. When trust is already compromised, then experts' claims to openness can readily be challenged as untrustworthy and lacking credibility. According to Brown and Michael then, there has been a shift from the problem of legitimacy to the problem of transparency in dominant models of PUS (2002).

The problem of transparency can be seen to have engendered an interesting rejoinder to the shift towards transparency in expert systems. That is, experts have adopted the discourse of emotion so that the performance of transparency is coupled with a performance of pain and emotion (Brown and Michael, 2002). As Brown and Michael have argued, the performance of pain and emotion involves expert claims to have gone to great and painful lengths to accommodate multiple voices. The views of organisations such as environmental, patient and other interest groups are considered, accommodated and incorporated as a gesture of openness, inclusion and, indeed, reflexivity. In order to convince the public that expert systems are open and transparent, the pain and suffering to experts as a result of their efforts to accomplish inclusion and transparency are offered as markers of authenticity, as Brown and Michael state:

> This is because suffering is grounded in the stresses, dilemma and tensions that emerge when a person or institution attempts to incorporate — give full voice to — the disparate, contradictory, antagonistic positions that contribute to the argument or controversy or risk assessment (Brown and Michael, 2002: 261).

Thus, the recourse to emotional discourse is an attempt to resolve the inherent limitations of transparency for redressing trust relations (2002: 261). Such strategies give the appearance of reflexivity, suggesting that cPUS research needs to investigate the extent to which this marks a shift in policymaking ideologies towards meaningfully including public groups and their views.

These institutional and rhetorical shifts seem to echo Beck's account of reflexive modernisation and risk society (Wynne, 2002: 466; see also Kerr and Cunningham-Burley, 1999). Scientific institutions are responding creatively to the growth of a risk consciousness and, correspondingly, the undermining of scientific certainty, expertise and cognitive authority. Inherent in reflexive modernisation is a dynamic 'learning process' that is achieved through complex 'flows of exchanges (goods, services, people, finance, information)' (Van Loon, 2002: 34-35). Following on from Beck, Van Loon has argued that expert systems (including science and technology) must be able to reflexively translate, incorporate and "hijack" other systems into their own in order to sustain their own existence (2002: 38). Similarly, Kember has referred

to scientists' increasing concern with competing sources of knowledge and how these can incorporated into the decision-making process as a 'newly adaptive biotechnological environment' (2002). This adaptability/reflexivity is exemplified by the adoption of new methods of public consultation practices that aim to improve public involvement, along with rhetorical shifts towards transparency and authenticity.

Whilst this shift towards authenticity and emotional discourse indicates how those in industry, regulation and elsewhere have recognised the failure of the authority in expert systems, as Brown and Michael cautioned, 'the actions warranted by emotion are not always benign' (2002: 270). This was similarly confirmed by Irwin, who found from his involvement in the qualitative phase of a public consultation exercise, that there are a number of limitations to such practices. For instance, non-scientists are not granted an active role in defining the agenda of consultation exercises, but instead this remains within the remit of official experts chosen by government. Irwin has also demonstrated the weak correspondence in the British context between policy concerns outlined during public consultation and the policy outcomes. If we also consider the shift towards transparency, it is notable that this model of PUS leaves the concept of 'science' unproblematised. Whilst in acknowledging the existence of alternative knowledges and perspectives, science continues to be grounded in notions of scientific certainty, empirical accuracy and objectivity. Furthermore, the performance of transparency does not necessarily challenge the authority of expertise but reinforces scientists' role as adjudicators and legislators of public views on science.

In a similar vein, Wynne has argued that even where there is an 'apparent cohesion' between different social worlds, public meanings are often translated into science's 'own restricted one-dimensional terms' or denied entirely (2002: 461, see also Kember, 2002). Only those risks that are defined by scientific institutions – and therefore *known* – are regarded as legitimate (Wynne, 2002). Unknown and ambiguous public meanings of risks – which Grove-White refers to as 'unknown unknowns' (cited in Wynne, 2002: 469) – continue to be viewed as 'intellectually vacuous and thus secondary, ethical or trust concerns' (2002: 466). Ironically, in the name of self-reflexive scientific rationality, experts have keenly developed and engaged with new forms of public consultation exercises, only for rich public meanings to be translated into non-reflexive discourses (Wynne, 2002: 463). In spite of the recent shift in rhetoric and the adoption of experimental models of public engagement, critical approaches have revealed that the deficit model lingers on in expert systems approach to PUS.

4.5 An Analytical Starting Point

It seems that reflexive modernisation processes are deeply ambivalent; containing both a radical potential for decoupling power from expert systems and a hegemonic potential where reflexivity is, itself, mobilised in order to shore up existing social systems (Kerr and Cunningham-Burley, 1999). Whilst transparency and emotional discourses may be understood as reflexive responses to changing science-public relations in the context of risk and controversy, they could equally be seen as non-reflexive because they are attempts to shore up traditional notions of expertise. Here, there is a tension between reflexive processes and reflexive outcomes. Again, this returns us to Beck's point that reflexive modernisation is a transitional, contradictory phase - caught between simple and reflexive modernity.

This tension that is inherent in reflexive modernisation has been explored by Kerr and Cunningham-Burley with respect to the new human genetics (1999). Their analysis of professionals' and publics' discourses of the new human genetics provides an empirical basis upon which to examine theories of reflexive modernisation and risk. They conclude that whilst there is evidence of a move towards reflexive practices and values within science, the radical potential of reflexive modernisation is limited. Professionals' institutional reflexivity are shown to protect their cognitive authority by constraining lay ambivalence (Kerr and Cunningham-Burley, 1999: 297). At the same time, however, they point to a paradox where scientists are themselves increasingly critical of the new genetics, such as eugenic practices. To some extent, then, they concur with Beck that reflexive modernisation is, indeed, a contradictory phase characterised by both simple and reflexive practices and values.

In building upon such analyses, my research also aims to capture the paradoxes of reflexive modernisation. Furthermore, like Kerr and Cunningham-Burley, I believe that sociological analyses of SCR and cloning can 'generate doubt and highlight uncertainty in contemporary practices, debunk professional claims to neutrality ... thereby disrupting professionals' rhetoric and fostering greater lay ambivalence' (1999: 298). Sociological research, then, can contribute to and further reflexive processes by engaging with both scientists and publics. By maintaining this tension between 'tradition' and reflexivity in our analysis and identifying instances of both, as Wynne has also argued, sociologists can begin to 'prise open these scientific, risk and environment-consequences cultures, so as to invite democratic entry' (Wynne, 2002: 472; see also Kerr and Cunningham-Burley, 1999; Kerr *et al.*, 1997; 1998a; 1998b; Cunningham-Burley and Kerr, 1999). Key questions then become: Have reflexive modernisation processes transformed and reconfigured expert-lay relations in science and technology, or has reflexivity

become another political strategy within scientists' accounts? What counts as 'expertise' in both scientists' and publics' accounts and why? Are certain forms of experience and understanding excluded from scientists' accounts and, if so, how? Such questions take us towards an approach that problematises rather than reifies recent cultural developments and institutional innovations for analysing the relationship between experts and non-experts, science and society.

CHAPTER V

Flexible Boundaries in Scientists' Discourses: Expertise, Uncertainty and Authority

5.1 Stem Cell Research and Cloning: 'Once More into the Breach'

As already outlined in previous chapters, the status and role of science in society were perceived to be undergoing transformations. At the same time, key protagonists within the SCR and cloning debates believed the debate could, potentially, make or break the future of this area of science. Against this backdrop to the public debates on SCR and cloning, it is interesting to explore how scientists have mobilised a range of rhetorical resources and strategies in order to manage and resolve elements of this controversy. The work of social scientists Gilbert and Mulkay (1984) and Gieryn (1995) has demonstrated the importance of analysing the range of rhetorical devices and repertoires used by scientists in constructing and maintaining the dominance, legitimacy and credibility of science and scientific knowledge. By analysing what scientists say, we can identify how rhetorical devices, discourses and boundary constructions are used in order to construct particular 'versions' of scientific practices, as well as 'constituting themselves as particular sorts of actors, [whilst] simultaneously constructing others around them' (Michael, 1996a: 79). Before discussing my empirical findings, it is worth reflecting on what makes the case of the SCR and cloning debates particularly interesting to the social scientific researcher in this respect.

Within controversial science such as SCR and cloning, core-scientists must *publicly* debate the scientific and social dimensions to their work at a time when scientific consensus is yet to be reached, rather than being played out within the laboratory between core-scientists, or even between core-scientists and the wider scientific community (see Collins and Evans, 2002; also Jasanoff, 1987).[1] The conventional images of science and technology as 'mechanical, rule-following behaviour' (Wynne, 1988: 148) are, in turn, undermined because the 'core' of science

[1] This is taken from Collins and Evans (2002) who distinguish between core-scientists and the wider scientific community. Core-scientists refer to those scientists who are 'deeply involved in experimentation or theorization which is directly relevant to a scientific controversy or debate' (2002: 242). In the case of eSCR, core-scientists include all those scientists interviewed as part of this research. And, as I will show, membership of the core-scientists is a highly political issue.

is publicly exposed and 'everyone gets to see the soft flesh of the scientific fruit and the familiar passions and arguments that constitute it' (Collins and Evans, 2002: 248). To this extent, the SCR and cloning debates can be seen as a 'breaching experiment'.[2] That is, traditional public presentations of science are breached, revealing that science does not have a homogeneous voice. In constructing the credibility and legitimacy of their own and others' work, scientists tend to rely on everyday criteria - such as who has developed a positive reputation, where people have published their work, who is deemed trustworthy and what their institutional affiliation is (Collins, 1987: 691). Thus, once the black box of science has been opened, revealing the 'extra-scientific factors' of scientists' argumentation, then taken-for-granted dichotomies between expert and non-expert knowledge and between scientists and non-scientists become destabilised (Collins and Evans, 2002: 239).

As we have already seen in chapter 3, controversies over SCR and cloning have not only take place within the field of science, but also between other fields such as politics, law, ethics, medicine, social sciences and an array of lobbyists. In this situation, scientific institutions are no longer the only sources of accredited knowledge on SCR and cloning, but instead are subject to scrutiny and scepticism by different professions and groups, each bringing different kinds of expertises and framing the debate according to their own terms of reference.[3] Scientists' power to define science and its practices, along with 'its authoritative status of providing 'truths' about the natural [and social] worlds' comes under threat (Jasanoff, 1987: 196). Collins and Evan argue that under these circumstances, where scientific controversies are played out in public before consensus has developed, the status of science is (potentially) undermined (2000: 247). To borrow Latour's Machiavellian metaphor, the struggle within the palace between the Prince and his own collaborators requires relatively soft techniques compared to the feroricity of struggles between the Prince and others outside the palace who say they are the Prince (1988).

In sum, disruption or breakdown in 'normal' social relationships and rules - in terms of science-public relations, the status of scientific knowledge and the public presentation of science - can be seen as a 'breaching experiment' which offers an insight into how social actors construct,

---

[2] A 'breaching experiment', as originally coined by Garfinkel (1963, cited in Collins and Evans, 2002: n33), is a methodological experiment that was designed as a means for exploring how actors respond to violations of 'normal' social relations across a range of social interactions. In the experiment, an individual breaks social rules through engaging in what is deemed to be inappropriate behaviour to the particular social context, in order to study others' responses to this. However, in the case of SCR and cloning debates, rather than the researcher creating an experiment, these are 'naturally' occurring.

[3] Similarly, Van Loon has argued that in debates around recent health-related issues such as BSE/CJD, 'scientific, political and legal arguments often operate on totally different grounds, leading to a highly complex web of discursive assertions and debates' (2002:201).

negotiate, legitimate and reproduce particular discourses and practices (see Barnes and Edge, 1982: 234; Jasanoff, 1987: 197). It is not enough for scientists working on SCR and cloning to simply establish themselves as credible experts (although this remains extremely important); they must also engage in processes of recruitment, translation and mobilisation in order to construct a powerful and convincing justification (see Chapter 3). To this end, risk and trust become important factors to be managed and negotiated by scientists. As we shall see, scientists' participation in public debates involves a range of tactics and strategies that are not necessarily coherent, but instead are often contradictory. By examining their discursive constructions of SCR and cloning, we can identify the variability of interpretative repertoires that are mobilised, as well as gaining an insight into the kinds of interests that are at stake.

5.1.1 A Note on Methodology and Structure

In the following chapter I explore a number of key analytical themes that emerged from interviews with five core-eSCR-scientists. As already outlined in Chapter 2, scientists included in this research were identified because of their prominent role either in the public debates and/or they are involved in developing embryonic stem cell research. Whilst I encountered some problems in gaining access to key scientists working in the area of SCR and cloning, those that did agree to be interviewed offered a great deal of insight into the range of issues regarded as pertinent to the debates and there was some convergence between views. All interviews took place between May and November 2001 – the year that the 1990 HFE Act was amended. The timing of the interviews meant that the public debates (including those in Parliament) were fresh in their minds. Austin Smith and Ian Wilmut, in particular, had spent a great deal of time speaking to politicians, journalists and participating in public debates. Consequently, scientists had rehearsed their views and had had time to refine their positions over the previous months.

This then raised the issue of how, as a sociologist, I could get beyond scientists' accounts as pre-rehearsed 'public relations' exercises. Following on from the work of Kerr *et al.* (1997) and Cunningham-Burley and Kerr (1999), this chapter explores scientists' accounts of SCR and cloning, and how they account for the social and ethical implications of scientific developments in this area. As in the afore mentioned research, I also draw upon and combine the approaches of Gilbert and Mulkay (1984) in *Opening Pandora's Box* and Gieryn's concept of 'boundary work' (1983; 1995). Gilbert and Mulkay's work is analytically and methodologically instructive for understanding scientists accounts, not as 'definitive versions' of scientific knowledge and other areas of social life, but instead to look for the 'multiple and divergent versions' generated by scientists (1984: 2). As already outlined in chapter 3, it is important to identify discursive

regularities within scientists' accounts and to be sensitive to interpretive variability. For instance, I will highlight some of the rhetorical strategies mobilised by scientists when accounting for uncertainty, risks and the social and ethical implications of their own and others' work.

Here, Gieryn's 'boundary work' is a useful analytical concept for investigating how scientists (re)construct boundaries between science/society, expert/non-expert, inside/outside in order to negotiate their position and professional status, as well as that of science more generally. As Cunningham-Burley and Kerr have argued, such distinctions are a result of the complex 'interplay of a range of professionals' interests', which serve to preserve and promote the privileged status of scientists as experts (1999: 648). In taking such an approach as my starting point, this chapter extends the work of Cunningham-Burley and Kerr (1999) and Kerr *et al.* (1997) by showing how, whilst such boundary work continue to be found in scientists' accounts, they have becoming blurred within the SCR and cloning debates. As I reveal, scientists construct boundaries as 'there' yet negotiable, rather than firmly constructed.

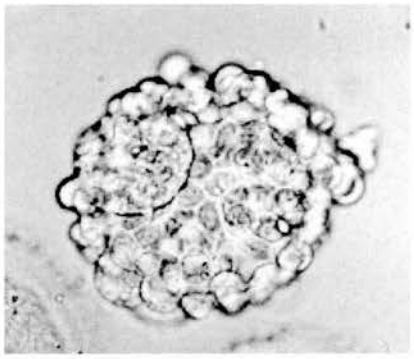
The chapter is organised around four sections in each of which I have identified rhetorical devices and discursive repertoires mobilised by scientists in their accounts of SCR and cloning. Broadly themed according to 'scientism', 'separating science and the social', 'separating stem cell research from cloning' and 'insiders and outsiders', I address wider issues – as constructed by the scientists – such as the use of embryos for SCR, differences between 'therapeutic' and 'reproductive' uses of the cloning technique and the role of publics in the debates. Where relevant, I relate my analysis of scientists' discourses to other aspects of the thesis.

5.2 Scientism

In this section I focus upon scientists' proclivity towards scientism when articulating their views of SCR and cloning. Scientism is 'the tendency to "convert" value issues into technical discussions ... [which] involves an attempt both to extend the *scope* of accepted expertise, and to establish its *scientific* pretensions' (Barnes and Edge, 1982: 244-245, original emphasis). Centred around the 'embryo question' and the rhetorical distinction between embryonic and adult SCR, I will show how scientists respond to social and ethical issues with scientific and technical explanations.[4]

[4] For the time being, I will leave aside issues relating to the socially constructed boundary which separates science and technology from society. This will be addressed in the following section.

As evident in the parliamentary debates (see Chapter 3), the use of human embryos in scientific and medical research continues to be an ethically sensitive issue. As such, the embryo question arises within scientists' accounts in the public domain, such as, public talks and 'educational' materials such as those found on the Internet. Within my interviews with scientists, the embryo question arises as a pre-identified ethical 'hotspot', which (as in the Parliamentary debates) tends to be converted from a value issue into a technical one. For instance, when giving public talks on SCR, Austin Smith uses a diagram of a blastocyst (a 6-8 day old embryo consisting of approximately 100 cells) in order to provide a technical description of how stem cells are derived (see below).[5]



Human Blastocyst
Source: *Institute for Stem Cell Research*, Edinburgh http://www.iscr.ed.ac.uk/stemcells.html

Crucial to this description is that the cells taken from the embryo are the inner cell mass that would form part of the foetus, not the outer layer of cells that gives rise to the placenta – the trophoblast. From here, Smith goes on to explain that without the trophoblast the embryo cannot connect with the maternal circulation and develop any further:

> So if you take these [inner cell mass] away, this [the embryo] can't really do anything more ... Once you take them out then they can't remake this [trophoblast] population of cells. So although they can, in culture, they can make the different types of cell that would make up a foetus, they can never acquire the proper organisation or develop any of the structures that you'd find in a foetus. Because that absolutely requires the support of the tissue and then the physical architecture that requires. And indeed, it provides some specific signals to trigger this to start developing in an organised way (Smith, Institute for Stem Cell Research, 15/05/01).

[5] I have been present on a number of occasions when Smith has used this diagram as an 'explanatory' tool, including at the Royal Society discussion meeting on Stem Cells, June 2001.

What Smith is emphasising here is that embryonic stem cells cannot continue dividing and become a foetus. By inserting a technical description of practices that take place within the laboratory, Smith is simultaneously pre-empting two key issues in the debates. Firstly, fears that this research may lead to reproductive cloning are allayed because the embryo is 'emptied' of the cells required to develop into a foetus. Secondly, stem cells are disconnected from their original source – the embryo – which can be seen as a move towards circumventing ethical debates about the relationship between stem cells, embryos and the 'question of life'.

In a similar vein to that noted above, John Clark, a scientist from the Roslin Institute stated that human embryonic stem cells are:

> Just like any human cell, they just happen to be made from an embryo ... So the fact that they are just cells that grow in culture and because of that, other than normal safety kind of things, there's no ethical regulations that apply to them (John Clark, Roslin Institute, 28/11/01).

The conversion of the status of embryonic stem cells into scientific and technical ones, renders the social and ethical issues redundant. As in the 1990 embryo debates, the ethical issues generated by the use of human embryos for research purposes and the arbitrary nature of the 14-day limit are averted by scientific and technical explanations (see Mulkay, 1997). Thus, constructing stem cells as distinct to embryos deletes non-scientific views of embryos (e.g., as life giving). It is interesting to note that this conception of stem cells also deletes the range of social relations and laboratory practices that go into producing stem cell lines. That is, the 'real-world conditions in which risks are actually experienced' (Wynne, 1996: 58-59), such as the involvement of those undergoing fertility treatment or the commercial exploitation of human embryos and cell lines. In displacing such actors and social relations, scientists are recreated as technical experts *and* as socially responsible.

The controversy over the development of adult SCR compared to embryonic SCR offers another site for us to explore scientists' tendency towards scientism. As an alternative to deriving stem cells from human embryos, adult stem cell research has received a great deal of attention from patient groups, anti-abortion groups, politicians and a number of scientists. When asked about this issue John Clark responded:

> There is a big debate going on, on the efficacy of embryonic stem cells versus adult stem cells but nobody knows yet. One thing I would say about embryonic stem cells, is that they certainly, from judging from what we know about them in mice, they can really do a lot. We really believe in them that they do have

> these properties. The properties of adult stem cells are far more debatable about how useful they will be (John Clark, Roslin Institute, 28/11/01).

As indicated in this quote, no ethical or social issues enter the 'debates', instead it is limited to scientific issues. This position is constructed from the starting point that the use of human embryos does not generate any problematic ethical or moral issues and, in turn, the embryonic versus adult stem cell debate is converted into one about expediency. Similar rhetorical manoeuvrings are made by Austin Smith in his response to a questionnaire issued by the European Commission's Temporary Committee on Human Genetics and Other New Technologies of Modern Medicine. After calling for both types of research to continue simultaneously, Smith argues that:

> Overall our understanding of and ability to manipulate embryonic stem cells is more advanced than for adult stem cells. Consequently there are compelling reasons to pursue human embryonic stem cell research and in fact there is no scientific rationale not to do so (Smith, 2001, original emphasis).

Whilst this seems to indicate that there may be non-scientific rationales for not continuing with eSCR, he then goes on to argue that social and ethical perspectives are irrelevant because research on human embryos is already permitted within the confines of the 1990 HFE Act. The underlining of 'scientific' rationale illustrates the reproduction of a hierarchy of knowledge, where scientific knowledge is separated from, and assigned higher status than, other forms of knowledge. That is, other forms of argumentation are acknowledged and yet science remains the *most* valid source of knowledge. By framing the debate according to scientific arguments, these quotes show how scientistic moves reinforce their 'scientific pretensions' within science and wider society by controlling the grounds on which this dispute is conducted, and the institutional forms by which any decisions or resolutions are reached (Barnes and Edge, 1982: 244).

Implicit in the above quotes is a usage of the 'truth will out' device. The truth will out device, as coined by Gilbert and Mulkay (1984), is a rhetorical device used to reconcile contradictory statements in order to maintain the appearance of consistency. For instance, on the one hand, core-scientists cannot *guarantee* that it is scientifically correct to state that embryonic stem cell research will be the 'better' option – in terms of expediency, developing therapies, etc. For this reason, scientists working on eSCR have supported the co-development of adult and embryonic stem cell research. On the other hand, both Smith and Clark argue that in the long run eSCR is more likely be the most useful scientifically. These arguments illustrate how scientists oscillate between strong and weak assertions about the certainty of scientific assessments of SCR (see

Gilbert and Mulkay, 1984: 93). Thus, the 'truth will out' device resolves contradictions that arise out of the tension between traditional notions of certainty and the uncertainty of 'real world' (reflexive) science by orienting us towards the future.[6]

5.3 Separating Science And 'The Social'

The conversion of social and ethical issues into scientific ones – scientism – often runs in conjunction with the exclusion or downplaying of non-scientific and non-technical issues. That is, scientism and the separation of science from the social are both part of the process of maintaining and reproducing the authority of scientific discourses (see Mulkay, 1979). Separating scientific from social aspects of SCR and cloning has been a powerful strategy in public debates. We can identify specific distinctions that both overlap and (often) contradict one another: therapeutic cloning/reproductive cloning, embryonic or adult SCR, SCR/therapeutic cloning.[7] A key discursive repertoire cutting across these distinctions is the construction of an idealised account of SCR that distinguishes non-scientific and technical issues from scientific ones: science from the social. However, the line between science and the social is a permeable one that is both contingent and negotiable (see Gieryn, 1995; Cunningham-Burley and Kerr, 1999). What are regarded as scientific and technological issues as opposed to social issues is neither fixed nor stable. The following section will explore interpretative repertoires mobilised by core-scientists for including or expelling non-scientific and technical issues.

Scientists working in or supporting the area of eSCR have invested a great deal of energy into constructing therapeutic cloning and reproductive cloning as two distinct techniques, each with their own set of social, moral and ethical issues. For instance, during the discussion with research students, RS1 remarked:

> We've come some way towards people making a distinction between cloning as in generating a person for spare parts and cloning as in making an army full of Hitler's to conquer the world, and cloning, as in something that will make a cell

[6] For a detailed exposition of the 'truth will out' device, see Gilbert and Mulkay (1984: 91-111).

[7] In addition to the distinctions that I have highlighted here, immediately after the announcement of Dolly the cloned sheep, scientists (including Ian Wilmut) 'separated the work on Dolly (defined as acceptable) from human cloning (defined as unacceptable and abhorrent)' (Einsiedel *et al.*, 2002: 329). However, the Dolly/human cloning distinction did not emerge as a dominant distinction within my own research which may be due to the three year time lag between the announcement of Dolly and my own research. During this time, debates around the potential medical applications of SCR and cloning had gained momentum, shifting the emphasis and agenda of public debates from 'Dolly' as the dominant signifier to the human embryo.

> type for you ... [where] they can take some skin and make cell types that your liver is meant for and they put them back in your liver (RS1, 16/10/01).

Here, RS1 identifies two types of cloning. The first refers to two future uses of reproductive cloning where cloned humans will be created to then be used for military purposes or for harvesting organs. The second type of cloning refers to 'therapeutic cloning' – the process of generating cloned tissue that matches the genetic profile of the recipient. Within the first account of cloning are two distinct narratives that have emerged within the media and the public imagination: Ira Levine's novel, *Boys From Brazil,* and the historical figures of Burke and Hare. Like Frankenstein, both narratives are potent cultural repertoires for expressing anxieties towards new areas of biological and genetic research (see Turney, 1998; Mulkay, 1997, Ch. 8). Each version of cloning is constructed according to available cultural narratives that are used to complete the as yet unfinished storyline of cloning developments. However, the usage of science narratives operates in this instance as a defence of therapeutic cloning 'by removing its opponents' objections from the sphere of fact to the cognitively inferior domain of fiction' (Mulkay, 1997: 121). Therapeutic cloning, then, is constructed as a legitimate and benevolent medical practice. Whilst the thrust of this quote was a defence of therapeutic cloning, reproductive cloning is portrayed as ethically problematic through its alignment with narratives of uncertainty and fear.

When I asked Ian Wilmut whether reproductive cloning is a separate issue to therapeutic uses of the cloning technique, he responded:

> I think that ethically you can [separate the two]. The ethical implications are different. Practically the same comments that you make about the safety of reproductive cloning should also make you wonder about the cells that you grow from those embryos as to whether they are also going to be abnormal. But we know so little about why clones are abnormal, well it's kind of difficult to predict. We don't know in many cases what the genes are, for example, so you can't even begin to predict, you know, that's important in the placenta so it's not going to be important for stem cells, or that's important for the organ but not important for this organ and these sorts of things ... So it does make you wonder how realistic those thoughts are at present time, or any thoughts are. But I do think that the ethical issues are very different actually (Ian Wilmut, Roslin Institute, 13/09/01).

Again, this statement rests upon the assumption that embryonic stem cells are ethically *un*problematic sources of stem cells. Thus, there is no further need to justify using human embryos for SCR (although references to potential cures serve as an implicit justification). By this connection, risks and uncertainties associated with eSCR are acknowledged and applied to the case of reproductive cloning without undermining the legitimacy of eSCR. This quote is a

further illustration of how the 'truth will out' device is used when accounting for error and uncertainty. Wilmut moves between an empiricist conception of scientific research on reproductive cloning and a more contingent (and to this extent, not entirely 'scientific') perspective that incorporates uncertainty and personal belief. Risks associated with the genetic abnormalities of cloned mammals are framed as practical issues rather than ethical ones. As practical problems they can be investigated, controlled and overcome by further research and development. Or, there would be enough information to say that such practices are not achievable for scientific and technical reasons. By separating scientific from ethical issues, the speaker formulates an argument that resolves contradictions between empiricist and contingent elements of eSCR, whilst simultaneously separating reproductive cloning from SCR. Hence, uncertainties associated with both therapeutic and reproductive cloning are mobilised to justify continuing development of eSCR.

SCR, then, is framed as a knowledge seeking enterprise with scientists simply employing their knowledge and skills for understanding and developing this area. In order to rhetorically construct this position, scientific and technical issues associated with SCR are detached from non-scientific and technical concerns:

> RS1 Is it scientists' responsibility? You know science is providing the tool, now how this tool is going to be used is to some extent the responsibility of all the legislation and the Government to control what can and cannot be done. You know, you can't blame [the person who] created the knife just because I took it and stabbed someone. It's just a tool. I can use it in a useful or a destructive way (RS1, 16/10/01).

By invoking the familiar use/abuse model, scientists' research activities are strategically separated from future 'negative' applications of any knowledge produced (see Kerr et al. 1997). According to this argument, scientists are simply engaged in objective, disinterested knowledge production. Such claims are important rhetorical strategies for constructing borders between science and politics. In the above quote, politics – science policy and related legislative matters – are outwith the realm of science. As argued by Gieryn (1995) it is important that the realms of science and politics are not seen to overlap and politics does not spill into science. Thus, the decoupling of SCR, as a disinterested knowledge source, from future applications and the issues that surround it, is an important and well established strategy for legitimating and maintaining credibility of scientists and their practices (see Barnes and Edge, 1982: 10).

This brings us to an interesting paradox in scientists' accounts: whilst SCR is decoupled from politics, it is simultaneously embedded in public health issues – a powerful trope in the political

domain. The potential medical applications of SCR and the implications upon public health and the economy has been one of the central features of core-scientists' accounts of eSCR for constructing this area as publicly acceptable and, therefore, eSCR-scientists as credible. In the parliamentary debates, for instance, scientists influenced the policy outcomes in their roles as expert advisors to government officials. Here, scientists gained control of regulatory decisions by explicitly extending the reach of their expertise. On other occasions, as noted in RS1's quote above, regulatory control is shifted back to government officials and related administrators (Gieryn, 1995: 438). Highlighting this contradiction shows the permeability of the science/politics border and, importantly, how these categories are mobilised as rhetorical devices 'through which distinctive interests of diverse players are advanced or thwarted' (Gieryn, 1995: 436).

When referring to the development of reproductive cloning, scientists interviewed as part of this research often blurred the boundary between science and the social. Whereas, during interviews, scientists have gone to great lengths to divorce social issues from scientific ones in the context of SCR, in the case of reproductive cloning, non-scientific arguments were readily mobilised. This is illustrated in the following, quotes from interviews with scientists which I have quoted fully because they illustrate the range of strategies used to link reproductive cloning to ethical issues:

> I think that [reproductive cloning] is nasty and I do think that ... it's wrong. It's very difficult to argue these things totally logically, you have to move to these things like intrinsic human beliefs and this sort of stuff and you might as well say that cloning is intrinsically bad because a) it's never going to be 100% perfect, so it's never going to be as good as IVF. So the easy argument is that you'll always have a substantially greater risk of abnormality. That's an easy cop-out. In many ways we have an intrinsic taboo. It should be a taboo and recognised as such. I think that we should recognise that some taboo's which are powerful and important in societies may not have, necessarily, a full rationality about them (John Clark, Roslin Institute, 28/11/01).

> I think that we as a society have a responsibility in some situations to say well this is just not allowable. This is just not ethically, morally or humanely acceptable and I can't see any, well to me, I can't imagine an argument that would make it acceptable to generate any embryo, cloned or non-cloned, and then implant it into a woman and then use it as a system for research. For me that's not tolerable, both because of what you would be doing to the, you would be using a woman as a vehicle for production of material and you would be using a much more potential human being than a pre-implantation embryo (Austin Smith, Institute for Stem Cell Research, 15/05/01).

> RS1 To clone a human you have to have hundreds and hundreds of egg donors. Donating eggs is not as trivial as donating sperm. It's quite more

invasive, so you have to get heaps of that. And then you have to get people who are prepared to receive an embryo, and that is not trivial at all ... OK and then they put it back in this black box and then they wait nine months and see what comes out. OK a lot of them will die. Most of them will die sometime within that period. A lot of them will die earlier. Some of them will die late. And to terminate a pregnancy is traumatic for the mother and the same mother will not do that again. OK maybe they'll do it twice. But then there are dangers to the mother, and the mother dies of complications. How many people is he [Antinori Sevorini] prepared to kill to do something that is useless?

RS2 And there's also the issue that children are going to be born who are potentially could be quite handicapped, either physically or mentally. I mean, how do you explain that to them - "I'm sorry you were an accident in an experiment"? I mean all the ethical issues that are wrapped up in it are just a nightmare. OK if it worked first time that would be good but I honestly don't think it will.

RS1 Even if it works first time it won't work every time.

RS2 No. You know with Dolly there were some that died early on.

RS1 The people that are going to volunteer for treatment they are going to be wanting to have fertility perfectly aware that the child, that potentially there is 1 out of 500 chance that they get a live child that is not severely handicapped, is not deformed. It could die later, a month later, 5 years later, 10 years later. OK it could make adulthood. But are they prepared to do that? (Research Students, 16/10/01).

Here, where they are arguing for limits on science, core-scientists extend their expertise for engaging with social issues relating to reproductive cloning – a U-turn from the construction of eSCR as disinterested, knowledge seeking scientific research. Non-scientific understandings take on a particular significance rather than being dismissed as 'opinion'. It is implicitly accepted that perceptions of reproductive cloning elude scientific rationality and explanation (explicitly in John Clark's quote), revealing the limits of such knowledge. In the exchange between the research students, however, issues of safety are paramount.[8] By focussing on uncertainties and risks relating to the survival and health of a cloned human being, as with Clark, the research students are also appealing to a sociocultural taboo – that of murder.[9] This reconceptualisation of the science/social boundary is evidence of the political skill of scientists in exploiting 'relevant social beliefs and attitudes in order to managed the public image of science so as to improve its political visibility and its capacity to evoke public support' (Ezrahi, 1971: 120, cited in Barnes and Edge, 1982: 238). Such evidence suggests that Cunningham-Burley and Kerr were

[8] There is an some interesting gender dimension to the quote from RS1. Risks identified corresponded to those experienced by women when donating eggs, undergoing terminations and 'complications' experienced during pregnancy – a rare occasion when the embodied experiences of women were foregrounded by eSCR advocates.

indeed correct when they argued that, 'operating with these boundaries [between science/society] ... involves scientists in both embracing and deflecting social concerns' (1999: 657).

5.4 Separating Stem Cell Research from Cloning

In the parliamentary debates and many other public discussions on SCR, eSCR advocates have framed their research in terms of potential medical applications of their work. In particular, combining eSCR with cloning techniques to develop 'therapeutic cloning' has been a powerful strategy because it offers to produce medical treatments for as yet untreatable conditions as well as circumventing present problems relating to immune rejection of transplanted tissues. By enlisting patient groups, diseases and various biological artefacts, 'cloning' has become an ally for scientists pursuing this area of research. During interviews with scientists it is interesting to observe the flexibility of the potential application of 'cloning', where 'therapeutic cloning' is strategically invoked and rejected. In the following section I will explore how 'cloning' is mobilised as a flexible resource in often contradictory ways.

Within the parliamentary debates, the development of personalised transplantable tissue was flagged as one of the main benefits that may come out of eSCR. Advocates for eSCR argued that scientists could produce replacement tissues that are perfectly matched to the recipients immune system so as to avoid the complications currently associated with tissue and organ transplants. Using cloning techniques, it was argued, scientists would create a cloned embryo using an adult cell taken from the person requiring the tissue, extract the stem cells, direct them into the appropriate tissue type and transplant them into the patient. This is the technique which came to be labelled 'therapeutic cloning', recently renamed 'patient-specific stem cell therapy' (see http://www.iscr.ed.ac.uk/stemcells.html). A striking feature to emerge from my interviews with scientists' was their claim that eSCR and its potential clinical applications does not necessarily involve cloning - which is a departure from one of the key strategies mobilised during parliamentary debates. For instance, Austin Smith referred to cloning as, 'a sort of add on that would make it a perfect therapy' (15/05/01). And whilst cloning would make it 'perfect', eSCR is argued as leading to potential medical therapies in its own right, regardless of cloning developments. Smith suggests that for diseases such as Parkinson's and Huntington's Disease, immunological rejection 'is not a critical thing'. He also adds that other areas of development

[9] Significantly, groups such as pro-life organisations have also utilised this argument in relation to uses of human embryos in SCR.

around immunology are being undertaken that 'might make transplants less prone to rejection' (Smith, Institute for Stem Cell Research, 15/05/01).[10]

A similar point was made by John Clark:

> Clark ES cells don't necessarily have anything to do with cloning.
>
> SP But at the point of application would that not be using the cloning technique?
>
> Clark No, not necessarily. Because, I mean it won't be, at least for the first applications of this. So really what you're talking about with human embryonic stem cells is cells that are prepared from human embryos and then grown in culture. And the normal way you do that, is take a human blastocyst that was surplus from an IVF fertility program, so the couple have given informed consent, so now it's worked, we've got our baby or whatever, we don't want these embryos anymore and they've given informed consent, etc., etc. That requires a license and everything. Then you would make, you'd take those embryos, maybe let them develop a bit more, maybe not, and then make the so called cell line from them. And then you grow that cell line in culture and that is essentially your starting material and you use those cells to make maybe a nerve cell, maybe a liver cell whatever it might be. Maybe a pancreatic cell. *But that doesn't involve cloning* (John Clark, Roslin Institute, 28/11/01).

I then pressed Clark on this issue, pointing out that within the parliamentary context and other public debates, scientists have focussed upon the potential of eSCR in producing therapies that were compatible with the recipients' immune system. Clark responded with technical explanations as to why eSCR may not solve the problem of transplanted materials being rejected by the immune system, stating that 'the jury is still out as to what will the incompatibility will be. We just don't know' (28/11/01). He then goes on to argue that therapeutic cloning, as a routine medical practice, is unlikely due to inefficiencies: it will require a large number of oocytes, will be expensive and will take too long. Indeed, contrary to the arguments outlined in parliament and other public debates, Clark dismisses the use of cloning techniques as a 'side issue'.

In both of the above transcripts, scientific and medical uncertainty is used to defer judgement about the future of SCR and cloning. Without being able to predict the future of SCR and cloning, scientists generate a range of claims and propositions that reflect their interests – and that of other core-scientists in their community – in continuing with their research (see also Chapter 3). Areas of uncertainty such as immunological rejection, how to make the process of 'therapeutic cloning' efficient enough to become financially feasible as a routine treatment, and

[10] For a description of the scientific practices involved in SCR, 'therapeutic' and 'reproductive' cloning, see Appendix II.

epidemiological issues relating to differences between diseases, are all raised as problems for scientists to overcome. However, rather than undermining the future of their research, scientists instead invoke uncertainty in order to separate cloning issues from eSCR. This is exemplified in the following quote from Austin Smith:

> One way of completely avoiding that problem [of transplanted materials being rejected] is through cloning, what's called somatic cell nuclear transfer. So in that case you may produce the stem cell from the patient who needs the transplant by transferring the nucleus into an oocyte. And we know that in mice we can do this, that you can make ES cells that way and probably at a reasonable efficiency. My bet is that with human cells it could actually be very efficient. A lot of people say, well, you know this will just be [...] so expensive it will only be applicable to millionaires in the US. I don't actually believe that, or at least I think that's open to question until you do the basic research to find out. And that's why you need the permission now to do the research rather than banning it [...] And so then, if cloning was efficient and the derivation of good stem cells from cloned embryos was efficient, then that would be a realistic treatment and it could well be cost-effective because immuno-suppression is not cheap (Austin Smith, Institute for Stem Cell Research, 15/05/01).

The thrust of this excerpt directs us towards the medical applications that may come from combining SCR and cloning. Within Smith's quote one can identify a number of key elements. Firstly, Smith extends his expertise to make a judgement on the relative financial costs of personalised stem cell therapies compared to existing immuno-suppression practices – an area where he is not a core-scientist. Secondly, arguments that stem cell therapies will be unaffordable to the general public – an argument often used by critics (see Sexton 1999) – is reclaimed and turned on its head in order to justify further research. Such a move can be understood as similar to Brown and Michael's recourse to emotion (2002) where Smith demonstrates that he has listened to different arguments, considered his position and come to a conclusion of sorts. Thirdly, uncertainty is mobilised as a flexible interpretative device. The uncertainty of the future of stem cell therapies allows Smith (and others) to speculate or even promote a certain amount of 'hype' and anticipation – again, constructing a market and a demand, as in the parliamentary debates.

The partial rhetorical separation of cloning from SCR has been particularly evident since the changes to the 1990 HFE Act came into place. Once the 'embryo question' had been resolved in Parliament then the prominent features of the repertoires employed by advocates of eSCR illustrate a shift in temporal emphasis – from a long-term to a short-term perspective. In removing 'cloning' from the 'story' of eSCR, scientists have refocused their accounts of SCR onto the present 'state' of research, and 'cloning' is rendered a future, potential development to be discussed when that point arises. As eSCR becomes increasingly entrenched as a legitimate

research practice it is no longer important to construct this area according to future medical benefits; instead scientists can safely address some issues of uncertainty – the legal debate has been settled (see chapter 3). However, we should note that a number of issues continue to be kept out of the public domain – such as animal rights issues relating to the use of mouse 'feeder cells' for growing human stem cells (e.g. the production of chimeras and their safety for use in the clinic).[11] The insertion of a temporal element is one component of the 'truth will out' device, enabling scientists to defer judgement whilst simultaneously reconciling contradictory arguments (Gilbert and Mulkay, 1984). As we saw in the above quote, by reverting to a description which isolates the current research from the larger picture, Smith offers a technical response to value questions and reinforces his scientific pretensions. Furthermore, uncertainty is redefined as a problem to be uncovered by scientific research and practices, thus reasserting scientific authority and expertise.

5.5 Insiders and Outsiders

5.5.1 Expelling Rogue Scientists

Previous analyses of scientific controversies have shown how participating scientists negotiate the inside/outside border on a number of different fronts, 'jealously guarding their power to define the public image of science, and warding off competing claims by rival disciplines' (Jasanoff, 1987: 196; see also, Van Dijck, 1998: 10-11; Gieryn, 1995). When there are many competing positions and arguments from within and outwith science, such as in the SCR and cloning debates, modes of representation that operate through processes of inclusion and exclusion become powerful strategies for (re)constructing expertise. That is, disciplinary approaches, groups and individuals are included and excluded from the 'bone fide' scientific community, endorsing or denying their 'rights' to make credible knowledge claims (see Gieryn, 1995: 424-29). The boundary work involved in securing these distinctions is tightly connected with securing expertise, trust and legitimacy – central to the concerns of eSCR advocates in fostering their interests.

Distinctions between inside and outside not only serve to keep the 'publics' out, but also can be used to expel fellow scientists who threaten the future of eSCR in some way. This is nowhere

[11] Here, I am referring to the cultures used to grow stem cells in the laboratory. At present, most stem cells are grown in cultures that contain cells from mice. This then raises the issue of whether any stem cells derived are chimeras because they have been 'contaminated' by cells from a species other than human.

more evident that when advocates of eSCR construct distinctions between SCR and therapeutic cloning, and reproductive cloning. Reproductive cloning is not only distinguished from eSCR in terms of scientific practices – that is, descriptions of the techniques and practices – but also in terms of the personnel involved. Scientists working towards developing reproductive cloning, such as Severino Antinori, Panos Zavos and Brigitte Boisselier – an infertility specialist, andrologist and biochemist respectively – have become the archetypal 'mad scientists' in this particular debate. Their expertise within their specific fields within science has made it difficult to dismiss their claims, but has required a number of strategies for excluding them from the 'legitimate' scientific community. 'Insiders' (core-scientists working on SCR or with experience in animal cloning) have been quick to point out that these scientists have no experience in cloning, thus rendering them as publicity-seeking amateurs, at best and irresponsible criminals, at worst (see also Nerlich and Clarke, 2003).

During the interview with Ian Wilmut I asked him about a recent trip to Washington where he had sat on a public panel on human reproductive cloning with Antinori, Zavos and Boisselier:

> SP Where you in Washington recently when Antinori ... [interrupted]?
>
> Wilmut: Aha! I view the world the other way round. Antinori was in Washington with me (Ian Wilmut, Roslin Institute, 13/09/01).

From the outset, Wilmut drew a clear distinction between credible scientists and non-credible scientists. By referring to his meeting with Antinori in this particular way, Wilmut is defining Antinori as an illegitimate poseur who is 'exploiting the authority that belongs only to bona fide occupants of the cultural space for science' (Gieryn, 1995: 432). In order to give his view more weight, Wimut's regard for Antinori as lacking credibility was presented as not only a personal view, but one also sanctioned by the wider scientific community:

> Wilmut: I think that [Antinori] has got an interesting track record, done some interesting things. I think that people who know think he's making a mistake in this regard at least. And it may or may not have anything to do with the Washington discussions and all of the publicity but there is a meeting in Monte Carlo in the program which was organised by the [International Association of Private Assisted Reproductive Technology Clinics and Laboratories] [...] of which he is a committee member and they've recently withdrawn on that basis. So I think that he really is losing credibility (Ian Wilmut, Roslin Institute, 13/09/01).

Here, Wilmut was referring to a forthcoming international conference on cloning, organised by Antinori – who has a proven track record as a fertility expert – which was subsequently

boycotted by fellow scientists and fertility experts and eventually cancelled. Antinori was also expelled from the organisation due to his public activities and support for reproductive cloning. What is being described here, is how Antinori's association with reproductive cloning has led to the withdrawal of support and recognition by his professional peers in an area which he is an established expert. Once expertise is divorced from credibility, this opens up a space to begin questioning the presence of expertise.

As in Gieryn's analysis of the case of Sir Cyril Burt, 'insiders' - such as Smith and Wilmut - distinguished Antinori's behaviour and intentions from the possible scientific validity of his findings (see Gieryn, 1995: 434). This is an important strategy, given that the techniques to clone a human being are the same as those used for cloning human embryos for patient-specific stem cell therapies.[12] 'Insiders', that is those working in the area of eSCR and animal cloning, stressed a number of risks involved in reproductive cloning, including health risks to the mother, child as well as 'social' risks, such as comparisons to eugenic practices - all of which were seen as crossing the line of acceptability (see Nerlich and Clarke, 2003). By focussing upon the health risks involved in human reproductive cloning, 'insiders' are constructing the limits of acceptability, which firmly places reproductive cloning outside of these. The establishment of limits contributes to the exclusion of reproductive cloners from the bone fide scientific community, which in turn prompts speculation as to the motivations of 'looney' pseudo-scientists for driving science 'out-of-control' (see Nerlich and Clarke, 2003).

The mechanisms by which scientists working on reproductive cloning have been marginalised echoes Adele Clarke's historical analysis of the development of contraceptives (2000). Clarke shows how reproductive scientists have, historically, been marginalised within the field of science because they were 'unable to create the separation between science and society' (2000: 39). Reproductive scientists have been hampered by the very nature of their subject matter - human reproduction. In this respect, their 'scientific and social/cultural illegitimacy' is rooted in broader concerns that 'reproduction is too much at the core of human social life for any tinkering in its processes to be ignored' (2000: 39). According to Clarke, scientists who

[12] It is noteworthy that during the interview with Ian Wilmut he informed me of an impending application to the HFEA to conduct human eSCR. Almost one year later it emerged that Wilmut and his team at Roslin had applied for a license to create cloned embryos to be used for medical testing (see Meek, 2002). This is a highly controversial practice as it would involve obtaining a large number of oocytes from women willing to donate them. Then removing the nucleus and replacing it with the nucleus of a cell donated from a person with, say, Parkinson's Disease. From this, human stem cells would hopefully be cultivated and then used for medical research. Whilst the research proposed by Wilmut and his colleagues does not involve implanting cloned embryos into women's wombs for gestation, this does extend beyond existing SCR that uses embryos donated from IVF treatment users.

developed contraceptives in the early twentieth century were characterised as 'mavericks' working at the margins of their discipline, concerned with effectiveness rather than safety, and, therefore, lacking in legitimacy (Clarke, 2000:66). Subsequently, new reproductive technologies have been subject to sustained criticism and resistance from feminists and women users for nearly 100 years, thus establishing a discursive repertoire that exposes the social dimensions and goals that underpin them.

In the case of reproductive cloning, it is interesting to note the incorporation of critical understandings of reproductive technologies into the repertoires of core-eSCR-scientists. The exclusion of scientists working on reproductive cloning from the scientific community has been achieved by embedding narratives of cloning within existing critical narratives that have troubled the demarcation between science and society, exposing the purposes and goals of the reproductive sciences. There is a convergence between core-eSCR-scientists accounts of reproductive cloning and many critical commentators. For instance Smith articulated his sense of unease that reproductive cloning 'would be using a woman as a vehicle for production' (15/05/01), and the research scientists were concerned that 'there are dangers to the mother' (16/10/01). This alignment of scientists discursive strategies with 'frameworks of opposition' (Kember, 2002) simultaneously distinguishes eSCR and its products from non-legitimate science (i.e. reproductive cloning), and protects the autonomy and professional authority of core-eSCR-scientists (see Gieryn, 1983).

The lack of trust and credibility assigned to those working on reproductive cloning has been further enabled because of the means by which their work and results have entered the public domain. For instance, over the Christmas holiday period of 2002, an organisation called Clonaid claimed to have produced the first cloned human being. This was subsequently dismissed as an elaborate public relations campaign by both core-eSCR-scientists, such as Ian Wilmut and Austin Smith, and reproductive cloner, Panayiotis Zavos. That Cloneaid scientists announced their work via the media rather than adhering to the conventional procedures of peer reviewed articles for diffusing scientific knowledge, contributed to their expulsion from the 'legitimate' scientific community. In a similar case, Zavos announced that he has produced the first cloned embryo to be used for reproductive cloning. Rather than releasing this via the media, however, Zavos is to publish a short report in *Reproductive BioMedicine Online* – whose chief editor is Robert Edwards, who co-developed IVF techniques with Patrick Steptoe in the 1970s (see RBM Online, June 2003). Robert Edwards has stated that the publication of Zavos' findings in *RBM Online* is a positive move towards 'openness'. By adhering to professional conventions such as publishing scientific findings within journals, suggests that Zavos is attempting to strategically

distance himself from his former colleague, Antinori – a performance of transparency in order to gain credibility and legitimacy within the field of reproductive medicine as well as within the wider public.

This suggests that traditional gatekeeping mechanisms and authentication procedures established to professionalise science continue to play a crucial role in policing the boundary between insiders and outsiders (see Jasanoff, 1987: 196). As illustrated above, the role of publishing one's findings within peer-reviewed journals serves a number of roles such as, establishing or affirming ones membership within a discipline, enabling scientists to scrutinise each other's work, and enabling refutation or verification to take place. However, publishing is only one of a number of mechanisms that is important for acquiring the status of insider, and other mechanisms can be enrolled in order to keep 'charlatans' out. For instance, in response to Zavos' announcement that his laboratory had produced a number of cloned embryos, Azim Surani – a developmental biologist at Cambridge, UK – argued that Zavos does not provide enough evidence of the procedures used in order to suggest that his work 'represents a real advance in knowledge'. In addition to this, Surani argued that Zavos' previous exaggerations of the statistical success of the cloning technique demonstrates that such claims cannot be trusted (Surani cited in Cohen and Carrington, 2003). The constitution of Zavos as untrustworthy illustrates how scientists rely on 'ordinary reasoning to bring their technical arguments to a conclusion' (Collins and Evans, 2002: 248). This suggests that publishing within peer-reviewed journals can be used to both include and exclude individuals from the scientific community and, moreover, can be achieved within the public domain (i.e. within journals and the science press). On this occasion, then, Zavos' performance of transparency was taken as an opportunity to publicly exclude reproductive cloning researchers from the 'legitimate' scientific community. The public sanctioning of deviants, according to Gieryn, is 'an opportunity for corrective public relations campaigns, restoring ... a belief that science on its own is capable of weeding out impostors (so hands off) and restoring confidence that science is really what genuine insiders say it is (nothing dirty is going on)' (1995: 432).

5.5.2 Excluding and Including the Publics

When carving up generic territories between inside and outside – science and non-science – scientists often revert to a simplistic model of how the public (mis)understand science, what it is and how it works. Specifically, core-eSCR-scientists' accounts of public uncertainty revolved around the public perception of *experimental* science. The perceived tension between 'insider' and 'outsider' perspectives of SCR is captured in the following quote:

> Smith: I guess that [clinicians] have to behave almost like they're God and just tell people 'this is it, this is the way things are done'. For a scientist, our training and professional lives are all about being critical and cautious. But the problem with that is that's no use to a politician or to a journalist or really even to the general public. You know, it's something contentious then they need to know with some conviction anyway, that there's, they certainly need to know what the purpose of the work is. What your aim is and that there's some likelihood of realising that aim. I think it's a delicate line, it's a delicate balance. You don't want to say that this will definitely provide a cure for Parkinson's Disease but I think that you have to say, I personally feel it's appropriate to say that this is, there is a realistic anticipation that this can provide a treatment for Parkinson's Disease and there really isn't much else on the table at the moment. [...] Every journalist I've ever done an interview with, they always finish with 'so when is this gonna be in the clinic?' because they have to put that in their pieces. I think they just always do that, and that's a very difficult question to answer (Austin Smith, Institute for Stem Cell Research, 15/05/01).

Similar views were also expressed within the discussion with research students:

> RS1 You know, with the CJD stuff, I think the most scary thing is for the public is not that the scientists ... have an idea what's going on, it's when a scientist says, well I don't actually have a clue. That actually is more scary than giving someone their basic research. I've read a few variant CJD papers about two years ago now, and they were like, 'well, we're not actually sure how it's transmitted yet and where it's come from'.
>
> RS2 Would you rather they lied?
>
> RS1 No I wouldn't rather they lied, but I think that if the emphasis is on scientists doing their research and this is where they've got so far but they still have to prove ... [interrupted]
>
> RS2 But people want the bottom line.
>
> RS1 Exactly, and there isn't a bottom line (Research Students, 16/10/01).

Uncertainty is cast as an inherent aspect of scientific research, which is at odds with presumption that 'the publics' who want science to provide certainty. This is a crafty rhetorical move, in effect arguing that scientific uncertainty is an indicator of responsible practices, and public uncertainty is translated as misunderstanding, thus reinforcing scientific authority. As Jasanoff has argued, '[m]uch of the authority of science in the twentieth century rests ... on its success in persuading decision-makers and the public that the Mertonian norms present an accurate picture of the way science 'really works'. Unlike politics, science is 'disinterested' and 'objective' and, unlike religion, it is 'sceptical' ' (1987: 196). By appealing to binary frameworks of insider/outside, science/public, lay/expert, scientists' accounts distinguish between two types of uncertainty that are formed according to the social location of the speaker - scientific

uncertainty and public uncertainty. Furthermore, this illustrates how the characteristics of science are flexibly constructed: on some occasions the preferred description of science is one of certainty, and on others scepticism and uncertainty are predominant features in scientists' accounts.

The examples of boundary work discussed so far has focussed upon how the demarcation of science from non-science serves to expel 'not-real members' from the midst of the 'legitimate' community of scientists (Gieryn, 1995: 432). In discussing how scientists are excluded from the core-set of scientists and the mechanisms by which this process is negotiated, I have highlighted how the drawing of boundaries between science and non-science depends upon the social context: Who, why and when? As we have seen, membership of the scientific community can be withdrawn by appealing to a range of mechanisms and processes that are already in place. Furthermore, the expulsion of members and all the public controversy that surrounds this, can reinforce the authority of a particular 'version' of scientific knowledge and reinstate public trust in the ability of science to regulate itself as an autonomous profession. The discussion of exclusion concluded with an example of how the inside/outside invoked as a repertoire for accounting for public mistrust and anxieties. Uncertainty, when expressed by non-scientists, becomes a cause for concern and management by eSCR advocates rather than being treated as a legitimate concern. In this respect, the boundary work that goes in to demarcating science from non-science serves to exclude public meanings that threaten the authority of core-scientists. In the following discussion, by contrast, I will turn my attention to the strategic *inclusion* of publics by 'insider' scientists. Significant to this discussion is how public uncertainty, when expressed by particular groups – patient groups – is mobilised in order to legitimate eSCR.

As already shown, the potential of SCR to provide treatments or cures for a range of conditions has been a powerful argument for constructing this area of scientific development as legitimate. On some occasions, scientists simply invoked patient groups as likely benefactors of SCR, thus inferring a benign motivation and a demand for stem cell therapies:

> Smith: Let's say you can use them for heart repair, for cardiac, so you could paste in cells that repairs damage to the heart – which is another promising area of ES cells because they make those types of cells quite easily and there's a big clinical demand (Austin Smith, Institute for Stem Cell Research, 15/05/01).

However, rather than simply invoking patient groups as a passive, silent 'market', Austin Smith also highlighted the lobbying activities of members of the Parkinson's Disease Society (PDS). For instance, after referring to the way in which journalists adhere to news values and ask for a

time frame when cures will be available, Smith goes on to compare this to the views of patient group members:

> Smith: Whereas, actually, the patients had a much more realistic appraisal of the situation and they, again, initially I found quite surprising, that people said this to me a couple of times now, that 'we just want to know that good research is going on and that, eventually, there may be a cure, even if it's not for us.
>
> SP Have you spoken to any other patient groups?
>
> Smith: Erm, no, actually no, just the Parkinson's people. They were the first to really come off the fence on this [SCR]. So that the medical charities are traditionally non-political, so they stayed out of this really until very close to the end. But the Parkinson's Disease people were, erm, got involved lobbying proactively quite early on and so they, through very different routes, both through the national PDS and the local branch, contacted me (Austin Smith, Institute for Stem Cell Research, 15/05/01).

Smith was keen to point out that, based upon his contact with PDS members, they were not interested in sensationalist media accounts, but instead wanted to engage in a 'realistic' assessment of SCR rather than wanting promises of stem cell therapies. That members of the PDS were deemed to be interested in knowing what research is taking place led Smith to re-evaluate his opinion of the involvement of patient groups in the stem cell debates. Significantly, PDS members, in their understanding of scientific uncertainty in the context of experimental science, could be seen to have acquired the status of 'experience-based' expertise (see Collins and Evans, 2002). That is, their embodied knowledge and experience of Parkinson's Disease is accepted as a type of expertise that is deemed to be credible and legitimate. Because of this, such patient groups are seen to have learnt about and gaining an understanding of 'the science' and how science works.

The overlapping of interests of patient group organisations and SCR advocates has served as a crucial legitimating repertoire. Across of number of contexts within the public debates, scientists have repeatedly turned to the lobbying activities of patient groups, diverting attention away from the motivations of scientists to the 'demands' of the public. For instance, when I asked about his involvement in the public debates on SCR, Smith says about his work:

> It sounds really grandiose to say [it's] important, but you know, you could see this could really make a difference to people (Austin Smith, Institute for Stem Cell Research, 15/05/01).

As in the parliamentary debates (see Chapter 3), by invoking patient groups as a potential user-group, scientists portray themselves as acting on behalf of the public. This enlistment,

translation and mobilisation of patient groups is also a powerful strategy for shaping the direction of public debates and counteracting any negative effects that the spectre of human cloning may have had upon eSCR (see Petersen, 2002: 84).

We should also note that similar strategies of invoking potential user-groups have been utilised by scientists involved in reproductive cloning. For instance, Antinori and Zavos began to refer to reproductive cloning as 'therapeutic cloning' when used to treat infertility. A further example of this is provided on Zavos' biography page on his website where he can be seen to be posing for photographs with Louise Brown – the first baby to be born through IVF treatment – and Robert Edwards – one of the two fertility specialists involved in Louise's birth and who has subsequently published Zavos' paper in his journal, *RBM Online*.

Louise Brown with Panayiotis Zavos
Source: http://www.zavos.org/drz.htm

Panayiotis Zavos and Robert Edwards
Source: http://www.zavos.org/drz.htm

This blurring of the boundary between reproductive cloning, IVF and SCR can be seen as an attempt to 'enhance their own image as fertility experts' (Nerlich and Clarke, 2003: 46) by inserting reproductive cloning into the narratives of less controversial techniques and practices.

However, according to Ian Wilmut, Antinori and Zavos' adoption of 'therapeutic cloning' regarded this as 'just mischievous' (Roslin Institute, 13/09/01). Indeed, as Nerlich and Clarke (2002) have also argued, this blurring of distinctions between fertility treatment, reproductive cloning and eSCR has facilitated the political and legal discussions within the UK and elsewhere.

My focus upon how scientists have mobilised the rhetoric of 'patient power', 'cures' and 'treatments' is not intended to suggest that scientists are cynically incorporating and deploying all means at their disposal. As Latour has argued, when a scientist (or in Latour's terms, 'the Prince') is engaged in many struggles, 'sometimes he [sic] exploits, sometimes rewards, sometimes lies, sometimes tells the truth, sometimes skills, sometimes deskills' (1988). Thus, the incorporation of the hopes and desires of patients into the rhetorical repertoires of SCR for legitimating its development, may indeed serve the interests of both parties. Boundaries between inside/outside, expert/lay, then, are not necessarily barriers 'to the inclusion of experience-based experts into the very heart of scientific decision-marking' (Collins and Evans, 2002: 264). However, an interesting dimension to this is that invoking the perspective of patient groups allows scientists to include emotional, experienced-based evidence into their own arguments, without threatening their own position as objective, disinterested researchers. By returning to the issue of 'experience-based expertise' in the following chapter, I will consider to what extent scientists' rhetoric flattens the complexity of patients views of SCR and cloning. On the one hand, scientists accounts of patient inclusion and influence in the development of SCR implies a more equal distribution of power between scientists and patient groups than actually exists. On the other hand, however, this may signal an opening for patient groups and social scientists to encourage greater public involvement in decision-making processes relating to SCR and cloning.

5.6 Conclusions

In this chapter I have shown how the SCR and cloning debates have produced a range of difficulties for scientists working within this field seeking to gain legitimacy for their research and maintain their status as experts. As outlined in chapter 4, the wider context of science-public relations appear to be moving beyond the 'traditional' PUS model and scientists can no longer assume the privileged position of 'expert' within scientific controversies. Consequently, there are a range of relevant social groups located both within and outwith the 'walls of the palace' with whom scientists must engage. Flowing from this, the already complex ethical issues are multiplied as different groups raise specific concerns that core-eSCR-scientists must be seen to address. Thrust into the public sphere at a time when scientific consensus, such as the continuing debates around embryonic and adult stem cell research, is yet to be reached, then,

scientists are negotiating the legitimacy of their research practices. Such negotiations have been shown to span scientific, technical, social and ethical concerns, in ways which generate a range of tensions and contradictions within scientists accounts of SCR. In turn, such contradictions are reconciled, or at least accommodated, with a number of rhetorical devices and discursive repertoires, such as scientism and 'the truth will out' device. What this chapter provides, then, is a nuanced analysis of scientists accounts of SCR and cloning.

In exploring scientists' discourses, one of the key points to have emerged from my analysis in this chapter, is how scientists appeal to various boundaries in order to constitute themselves as experts within this area. My analysis reveals how scientists' accounts of SCR and cloning rest upon an intricate weaving and borrowing between boundaries such as certainty/uncertainty, science/society, expert/non-expert, scientists/publics. Significantly, scientists appeal to both scientific authority and scientific expertise *as well as* uncertainty and experienced-based expertise. For example, when advocating the use of human embryos for SCR, Smith draws upon a technical description of pre-14-day embryos and uses disembodied images of 'blastocysts'. Technical accounts (based upon scientific 'knowledge') of embryos redefines embryos as cells to be manipulated and cultured, and eSCR is constructed as expediting the development of medical therapies. Here scientists' accounts of SCR are reasserted as authoritative and the legitimacy of alternative constructions of eSCR – such as those of people undergoing fertility treatment – are marginalised. At the same time, this privileging of scientists accounts is counterpoised by assigning expert status to some patient groups. That is, when patient groups mobilise their experiences of illness as a mechanism for advocating eSCR, scientists such as Austin Smith readily accept this 'experienced-based expertise' (Collins and Evans, 2002) as legitimate 'knowledge'.

The nuances of scientists' construction of expertise was also identified in core-eSCR-scientists negotiation of inside/outside boundaries when expelling reproductive cloners such as Antinori. As I have argued, it was important for SCR advocates to separate eSCR and 'therapeutic cloning' from 'reproductive cloning'. And in order to construct such distinctions, a range of rhetorical repertoires and devices were mobilised such as aligning eSCR with the rhetoric of hope, and reproductive cloning with fear. In doing so, core-eSCR-scientists were posited as socially responsible, whilst those working on reproductive cloning were regarded as irresponsible mavericks who are potentially risking people's lives. It is interesting to note that the expulsion of Antinori could not be achieved by casting Antinori as a 'bad' scientist, which, if we consider Wilmut's view, is perhaps because his credentials as a fertility expert precluded this. Instead, 'cloners' such as Antinori are posited as going beyond the boundaries of what is

publicly acceptable and, therefore, sanctioning occurs through appealing to social dimensions rather than scientific ones. To this extent, it becomes difficult to talk about scientists as simply pursuing professional interests; rather, these co-exist with other concerns (e.g. ethical). For instance, Smith was concerned about exploiting women's bodies for reproductive cloning and the research students discuss the health risks to both mother and child in reproductive cloning. It is significant, of course, that the articulation of risks related, primarily, to reproductive cloning rather than eSCR or 'therapeutic cloning'.

A final point to make within this chapter relates to the extent to which scientists' discourses meaningfully include the voices of other relevant social groups. As I have shown, some core-eSCR-scientists have, indeed, appealed to the experienced-based expertise of patients. However, there remains a tendency to marginalise the views of people undergoing fertility treatment (potential embryo donors) and to uncritically invoke patient groups as allies. Little attention is paid to public ambivalence or risks other than those framed by scientists. For instance, issues around commercial interests in SCR or people's embodied relationships to embryos are excluded from scientists' accounts. To this extent, most public voices are excluded as non-legitimate experts. Only some patients' experiences are included as legitimate and then only some patients – for instance, only patients who belong to organisations that have publicly supported eSCR – and any 'dissenting' voices within such organisations remain excluded. For this reason, in the following two chapters, I will present the views of members of these other relevant social groups, exploring the range of issues and discursive repertoires mobilised by them.

CHAPTER VI

Public Perceptions of Stem Cell Research and Cloning: Expertise, Risk, Trust and Ambivalence

6.1 Moving Beyond the Polarised Debates

As already noted in previous chapters, the public debates on SCR and cloning-related developments have become polarised. The framing of the debates in Parliament (see Chapter 3), scientists' accounts (see Chapter 5) and media reporting of the debates (see Williams *et al.*, 2003; Hargreaves *et al.*, 2003), have tended to exclude the complex views and experiences of a range of relevant social groups. Where the views of non-scientist publics have been included they tend to be incorporated into pre-defined discourses. For instance, as shown in Chapters 3 (section 3.4) and 5 (section 5.6.2), patient groups are mobilised as a 'desperate' market, demanding stem cell therapies. Similarly, people undergoing fertility treatment are enlisted as willing participants in the stem cell network (see section 3.5). The support of both potential embryo donors and user-groups for SCR and cloning-related 'therapeutic' developments are unquestioned and their identities are delimited.

The characterisation of patient groups as unequivocal in their support for SCR has been fostered by some patient organisations. Both individual organisations (e.g., Diabetes UK and the Parkinson's Disease Society) and umbrella organisations (e.g., the Genetics Interest Group and Association of Medical Research Charities) have been vocal in the stem cell debates – for example, by responding to policy documents, attending relevant conferences, and providing press releases and other documents on their websites. Furthermore, as we have seen in chapter 5 (section 5.6.2) and in public debates, pro-eSCR advocates argue that patient organisations have actively lobbied scientists and politicians and, in doing so, were instrumental in the 2001 amendment to the 1990 HFE Act. In this sense, then, patient organisations seem to occupy a key position in the politics of SCR and cloning-related developments, and have become part of the policy community. In the broader context of patient-doctor relations, however, Salter has questioned whether there really is a transformation in the dominant ideology of the policy community 'towards an acceptance of an enhanced role for patients in policy making' (2003: 928). He argues that patient inclusion in the policy process has become a 'central ideological symbol ... to legitimise policy making by the use of a political language which constantly

reiterates a particular theme: in this case, that the public plays a central role in both the policy process and its outcomes' (2003: 931). If we consider how patient groups have been rhetorically invoked and mobilised by eSCR advocates in the SCR debates, this does seem to echo Salter's point.

The criticism can be taken one step further, on the basis of the contact I have had with members of the local branches of patient organisations. This aspect of my research challenges the presumption that patient organisations, lobbyists or spokespeople *represent* the views of their members in any literal sense. For instance, during discussions with patient support groups many of the participants said that they had not thought about the issues of SCR and cloning or identified this as an area of research that had any relevance to their own (future) healthcare. It became clear that the members of local patient groups I spoke to had not been consulted by the wider organisation before they gave their public support to SCR.[1] It is against this backdrop, then, that this chapter explores the views of relevant social groups. By analysing and comparing the accounts of participants in two infertility support groups, four patient support groups and two individual interviews with members of an Alzheimer's support group, I will attend to the various discursive mechanisms mobilised for negotiating issues of expertise, risk and trust. In keeping with a cPUS approach I will show how the complexities of public understanding of SCR and cloning cannot be captured by research that attempts to gauge the levels of 'technical' or 'scientific' knowledge held by individuals. Instead, this chapter focuses upon the rich array of cultural resources, meanings and interpretations that are 'brought to the table' during discussions on this topic that 'mediate and reflect local cultural conditions' (Michael, 1998: 314). Such discussions also reveal the extent to which participants' views are contradictory and ambivalent, differing both within and across groups.

The overall approach for analysing these publics' accounts is similar to that adopted in the previous chapter. As with scientists' accounts of the SCR and cloning debates, I focus upon the rhetorical devices mobilised by participants in the patient support groups and highlight some of the dominant issues and tensions that emerged within the discussions. In doing so, my analysis

[1] One known exception to this is Diabetes UK which organised a discussion meeting with some of its members. The meeting consisted of a briefing paper along with some 'experts' talking about the science and ethics of SCR, and a panel discussion. Following on from this, delegates moved into small groups in order to discuss their views on the issues. The overall aim of the day was to consider the role of Diabetes UK in the debates and whether it should fund both adult and/or embryonic SCR or lobby for a change in the regulatory framework. However, it should be noted that none of the members who belonged to the branch which participated in my research were invited to, or aware of the Diabetes UK discussion meeting before it took place. This meeting also took place over six months after the 1990 Act was amended.

shows how, in contrast to the scientists' accounts, the publics' views of SCR and cloning 'open up' the debates, offering alternative ways for framing the issues and identifying problematic aspects of these developments. Participants within the various patient support groups were not restricted by concerns to legitimate this area of research (although this was an issue for some participants), but instead explored the various implications in some detail, outlining both their hopes and fears. The views held by members of these relevant social groups are shown to be contradictory and ambivalent, and cannot be pigeonholed as either for or against. What the focus group discussions reveal is a tension between a pervading sense of uncertainty and more optimistic belief in the potential of science, technology and medicine to develop new treatments or cures.

This chapter builds upon existing work that explores how people negotiate the promises and risks of the new human genetics. For instance, research conducted by Kerr, Cunningham-Burley and Amos on lay people's views on the new human genetics has focussed upon the use of metaphors of 'drawing the line' as a way of expressing and exploring ambivalence (see 1998a; 1998b). Directly influenced by cPUS research, their research has illustrated the inadequacies and inappropriateness of approaches that seek to produce resolute expressions of public opinion (such as opinion polls and attitudes surveys) or to measure people's knowledge levels of 'scientific facts' as indicators of public understanding. Public understandings are, instead, shown to be complex, ambivalent, shaped, as the work of Wynne and others indicates, by their experiences and social situatedness. The work of Kerr *et al.* demonstrates how 'any clear boundary between good and bad practice [in genetic science] remained elusive and slippery' (1998a: 130) in the eyes of non-scientists. They find that people raise a range of issues including genetic determinism, medicalisation and wider social prejudices and inequalities (e.g. the stigmatization of disability or abortion) when formulating their views of acceptable and unacceptable areas of genetic research. The significance of such issues is that they were used by participants to point to the grey areas of the new human genetics that make 'drawing the line' difficult.

In a similar vein to Kerr *et al.*, Susanne Lundin has explored the range of views and everyday strategies adopted by patients participating in clinical trials for xenotransplantation (2002).[2] Lundin investigates how people negotiate their understandings of the potential consequences of animal-to-human transplantations (such as health risks and the destabilisation of cultural categories) and connects these to their embodied situatedness of illness. In particular, she shows

[2] Xenotransplantation refers to the practice of using organs or tissues from one species, usually an animal, for transplantation into another, usually human, for therapeutic purposes.

how the entrenchment of new therapies is not characterised by wholesale acceptance and support but instead is achieved through complex negotiations over hopes and fears. Patients' ambivalence towards xenotransplantation reveals how all-embracing ethical principles, such as attitudes towards animal research, are renegotiated, thus demonstrating that values are flexible and are often intricately contingent on specific contexts (Lundin, 2002: 341).

Located within cPUS approaches, this chapter explores how members of patient support groups negotiate the tension between the risks and promises of SCR and cloning-related developments. I will illustrate how participants' views are shaped by their embodied biographies and their understanding and experiences of the broader social context of expert-public relations. For instance, I will highlight the range of cultural resources and experiential knowledge that are inserted into discussions around distinctions between 'therapeutic' and 'reproductive' cloning. In linking the construction of SCR and cloning to the broader experiential and sociocultural context, I will show how issues of trust are central to the publics' views of the role and status of science in contemporary society.

6.2 'Therapeutic' and 'Reproductive' Cloning: The Slippery Slope

Alongside the 'return to the embryo question' (see chapters 3 and 5), the rhetorical separation of 'reproductive' and 'therapeutic' cloning has been central to the success of pro-eSCR advocates in bringing about the amendment to the 1990 HFE Act (see chapters 3 and 5). Accordingly, the creation of legitimacy in the area of SCR was accomplished by effectively drawing a line between these two uses of the cloning technique, and so averting 'slippery slope' arguments. Within the patient support groups, however, the line between reproductive and therapeutic cloning was regarded as problematic and participants tended to blur the two. Whilst, like the core-eSCR-scientists, they argued that therapeutic and reproductive cloning differed at the level of intention (one is to develop medical treatments and cures while the other is to create a cloned human being), this distinction was often undermined as the discussion developed. Within both fertility support groups, for instance, participants talked about this distinction a number of times in the discussion and in *the same breath* alluded to a 'slippery slope' relation between them:

> SP Do you think these [reproductive and therapeutic cloning] throw up different issues?
>
> F2W3 Yeah, I think that they do yeah.
>
> F2W2 You're talking about a part rather than a whole. To cure someone who is really ill so it doesn't [inaudible]. But cloning is extreme.

F2W4 One is sort of for giving new life, the other one is to satisfy someone's wishes.

[All agree]

F2W2 Yeah I think that it's only a matter of time before it [reproductive cloning] is done.

SP So you don't think that primary legislation will stop it?

F2W2 Hopefully it does, but if they can do it to a sheep.

And then again, later in the discussion:

F2W2 They're totally different. One is to cure, obviously, and the other is just out of curiosity – to see if it can be done.

F2W3 But I think that's probably right. I think that there may be a slippery slope – that once they've done one they'll just go on to do the other. I wouldn't be surprised if that happened. As you said [looking at F2W2] it's only a matter of time before they can, they obviously know they can clone animals so it's only a matter of time before they clone humans. I think there will be a slippery slope because we've opened the door on therapeutic cloning so it will only be a matter of time before it's used for reproduction. Somebody out there will do it (Sister-led Fertility Support Group, 27/06/01).

In this exchange of views, participants begin by drawing a clear line between reproductive and therapeutic cloning. This distinction is underpinned by a particular understanding of what constitutes a legitimate illness that, interestingly, excludes infertility. Their experiences of infertility treatment (W1, W2 and W3 were undergoing fertility treatment and W4 is the Sister within the unit that they attend) did not, in this instance, cause them to reflect upon what constitutes an illness.

Despite the perceived moral differences between therapeutic and reproductive uses of cloning techniques, both W2 and W3 argue that reproductive cloning will be developed. This sense of inevitability and powerlessness was also expressed by a number of participants across the patient support groups. Implicit in their accounts is an understanding of science as driving forwards in the pursuit of knowledge with little control or reflection upon the broader ethical and social issues. Similar views were also articulated in the patient-led fertility support group (19/06/01):

F1M4 This [reproductive cloning] is the next stage eh? It has to be. They have to go that way. You get progress don't you?

F1M3 It's like rolling a ball. You've got to go all they way ... [interrupted]

F1M4 Yep.

F1M3 ... [continuing] because if you create stem cells then you'll want to create an eye and the heart ... [interrupted]

F1M4 That's right.

F1M1 Yeah.

F1M3 ... [continuing] The only way you can do that is by totally, at the end of the day, is by cloning a whole human being. Just like rolling a ball down a hill.

F1M1 Yeah.

F1M4 That's what's happening now.

F1M2 I have a picture of something that I saw on the tele some time ago about growing earlobes on mice or something ... [interrupted]

[General recognition of mouse by group]

F1M2 It's abnormal that you know, growing false earlobes onto animals – and that's questionable. But you can understand as well why they're doing it. So you've got that dilemma. It [the ear] needs something in order to sustain it and keep it alive but, I don't know.

SP So do you think that if, I mean, the research on stem cells has been permitted. They've changed the legislation of the HFEA in January, do you think that if this becomes accepted and widely practised, I guess this is what you were suggesting, do you think that this will lead to reproductive cloning?

F1M4 I don't know. If you can do all these things to help people and that, you've got to go all the way. You can go so far.

F1M3 What I was trying to say is that the therapeutic side will get so far and they'll say "we can recreate skin for the burns victims". This will create far more pressure for the other side, reproductive cloning. They'll have far more pressure to keep on going, but at the end of the day it will happen. They will clone a human being once they've got the technology. Nothing can stop people from doing that. I'm not necessarily saying that's a bad thing but I think that people are kidding themselves if they think that's not scientists ultimate aim. They will do it, just to prove they can do it. Not necessarily for the therapeutic side to work, but they will do it. To my mind that's what will happen with cloning whether it be in this country or in another country.

F1M4 It'll be done somewhere.

In this long exchange between participants, the perception of cloning as an inevitability (using the metaphor of 'rolling a ball down a hill') is related to growing a human ear on the back of a mouse. On the one hand, this is used as a narrative device to present science as out-of-control and to reconfirm the perceived slippery slope from therapeutic to reproductive cloning. On the

other hand, whilst M2 regarded the image of the human ear on a mouse as abnormal, it was also seen as a necessary (albeit problematic) aspect of research for developing medical therapies. Scientific progress, it seems, was understood as intrinsically Faustian in nature, caught between potential therapeutic benefits and potential risks.

The linking of these two cases shows how the 'slippery slope' towards reproductive cloning is understood as both an inevitable consequence of SCR and therapeutic cloning, and yet an acceptable risk. Such a view was similarly articulated by W4 in the Sister-led fertility support group, who, after supporting SCR for the most part of the discussion went on to outline her concerns:

> F2W4 I think that my worry is that we are all prepared to take one little small step repeatedly. If we take a big leap from coming from IVF and going to cloning that's a huge, but you could take small steps for a number of years and suddenly cloning is only one final step further than what we are doing already. So I can see that anything you do now and find it acceptable ethically, erm, what you find is not ethically acceptable, it will be ethically acceptable in a few years time. Because you've gradually done a little bit more as it's gone along. So I don't think that you put a barrier and say this part of cloning is OK and this part is not (Sister-led Fertility Support Group, 27/06/01).

In this account, the 'slippery slope' occurs as new developments become entrenched and normalised. To this extent, F2W4 problematises the 'slippery slope' by presenting public 'ethics', or what is deemed as un/acceptable, as context specific and a shifting set of ideas rather than fixed across time. And it is by this connection that she links IVF, therapeutic cloning and reproductive cloning together as part of the same trajectory.

As in the patient-led fertility support group, a number of participants in the Huntington's support group also linked SCR and therapies with a other aspects of genetics in order to elaborate upon a 'slippery slope' argument:

> HM1 I think that we're concerned that it's unnatural replication. We've concerns about the research and where it leads it. You know, is this the start of cloning as such, where it moves from that? A wee bit about the effect that it has on engineering, as such, you know, where things are being manufactured. Obviously we're worried that it could prove a lot of benefits to people with medical conditions and that's certainly what would appear to be happening, in terms of doing this genetic design to try and find cures to certain illnesses. I suppose my main concern would be where it goes after that or if it gets into different hands or different countries or things like that (Huntington's Disease Support Group, 31/10/01).

Here, M1 articulates both his expectations of and anxieties towards SCR and cloning-related developments. Whilst M1 mobilises the slippery slope narrative as a device for imagining the future, his 'concerns' are not presented as *fait accompli*. Genetic engineering and reproductive cloning were regarded as risks, not inevitable consequences. This view typifies those offered in the Huntington's group discussion – where narratives of fear were mobilised as the antithesis to their own hopes and expectations for SCR and cloning-related developments. And despite any concerns regarding the perceived 'misuses' or ethical problems involved in SCR, members within the Huntington's support group were ardently in favour of SCR. At the end of the discussion (Huntington's Disease Support Group, 31/10/01), participants ended on a supportive note:

> HW2 Right, I think that we should draw this to a close because we're out of time. Has anybody else got anything to say?
>
> HW I was just going to say that anything that helps should be pursued and this is why it must go on.
>
> HW Oh yes, it must go on.
>
> HM I mean, fifty years from now, all these people wanting it to stop it happening, there'll be another problem.
>
> HW I suppose we're selfish too by wanting research to go on just to help us.
>
> HW1 Yes, but it must go on. We must go forward.

Again, like F2W4, there is an implicit understanding of the social and historical contingency of what are considered to be public ethics and risks. Indeed, the contingencies of what constitutes un/acceptable practices are used to legitimate the continuation of SCR. Contained within this account is an insight into the significance of their embodied biographies and lived experiences of Huntington's disease in shaping their views of this area of research.[3] Framed by discourses of progress, when risks – such as genetic engineering and reproductive cloning – are compared to the potential therapeutic uses of SCR, these are considered to be acceptable.

[3] Participants had varying lived experiences of Huntington's disease (HD), including being 'at risk', caring for partners with HD, some individuals had overt symptoms, and there was one retired scientist who had spent many years conducting research into HD. All members of the support group had a vested interest in the care, support and development of treatments for HD.

6.3 Regulation and Control: 'It'll Be Done Somewhere'

Continuing with theme of slippery slope, I will now pick up on the theme of regulation and control – a theme already implicit in some of the accounts discussed so far. The view that SCR and 'therapeutic' cloning would lead to human reproductive cloning was a key feature in all focus group discussions. Central to this, is the issue of the (in)efficacy of regulatory mechanisms in this area of science. Participants reflected upon the extent to which SCR and cloning-related developments can be controlled and the dynamics of contemporary science.

During the discussion in the Diabetes support group, participants talked about their images of reproductive cloning and the range of social, ethical and moral issues that this raised. In particular, reproductive cloning was compared to eugenics practices and, related to this, dog breeding:

> SP So what do you think frightens people so much about cloning humans?
>
> DM1 It's a guess, but just what uses could be made of what you've cloned? Whether you put it down to the sci-fi or ... [interrupted]
>
> DM2 Or if anyone who could remember back to the second world war and Hitler ... [interrupted]
>
> [DW2 and DW1 "I was just about to say that"]
>
> DM2 ... and the Arian nation. Six foot four, blonde and muscular erm, young men etc., etc., and young ladies to go with it. I think that was one of his [Hitler's] goals and I think is always something that people are very afraid of ever happening. Although not that it's likely to ever happen, but that fear is buried in peoples' sub-conscience probably throughout the world – or throughout the world that knows of the second world war.
>
> DW2 It [reproductive cloning] was probably what they were working on with all these people who were gassed. They were probably trying that out even then. Not succeeding of course but that was probably behind Hitler's strategy.
>
> DM3 Are you saying that that wouldn't happen over-the-way [in scientific laboratories]? But the way people look at life now, especially cloning, now there's Dolly the Sheep and, actually, I know some dog-owners that are trying to get the perfect breed. They continue to breed and interbreed and interbreed until they've got this specimen that "that is it" and when you say that wouldn't happen I can sort of picture in years to come there will be the white coats working through this. Getting the perfect six-foot-four [LAUGHS]. It's just, when you say it can't happen and when you consider how do you get an aeroplane off the ground? How do you get a car to move? And you say well, we've actually done that and there's been somebody on the moon. Could it happen? I mean we are getting the technology.

DM2 Sure, sure. I think that probably the technology is there but I suspect that the outcry from the general public and the informed public would be such that ...

DM3 I was thinking just before you got up about Hitler in the '30s, his thinking. But now we're in the 2000s now and look at the distance we've come. So therefore what's to say in another 70 years that somebody else is coming up? (Diabetes Support Group, 26/09/01).

One of the significant aspects of this exchange is the comparison of reproductive cloning to eugenics to illustrate that controversial practices have been allowed to take place. It is not only that reproductive cloning is reminiscent of eugenics and 'breeding' practices, but that eugenics provides an empirical basis on which to found concerns about the slippery slope. Public outcry is not reckoned to prevent scientists working in and developing controversial areas of medical research, indicating a sense of powerlessness to alter the direction of science, technology and medicine.

Following on this, I asked whether they thought that primary legislation to prevent reproductive cloning would be effective:

DM2 No, no of course not. No. I mean there's legislation against terrorists, if I can mention that, but that doesn't help. You can legislate until you're blue in the face but someone will always ... [interrupted]

DW1 People always find a way around it don't they, yeah? I still don't think that it's a reason to stop the therapeutic side.

DM2 Yes, I would agree with that.

DW1 I think that anything that helps people who have chronic illness can only be for the good. I'm not speaking as somebody who has Diabetes because I don't have it but my husband had and I could see the effects that it had on him. If only that technique [stem cell therapy] had been around to stop that then it would have been wonderful. I could only wish for people who are in that position.

DM2 That, I think, is very much an informed comment. Going back to what I said earlier, if you put these questions to the general public you tend to get an affirmative answer for cloning and reproductive research from people who have been affected somewhere in the family by chronic illness. But other people who have healthy families and who never had a day off work in their lives quite often don't see the necessity or the requirement for it.

DM3 I think that the difficulty I have with it is just where do they close, where does it stop? You mentioned earlier, how far, I mean, once a stem cell, there's a cure for Diabetes, then somebody takes a step further, a step further, a step further, a step further. That, I think, is the difficulty people have. Just where will it stop? and again, you mentioned Government legislation and I

mean, there's a lot of things happen when they shouldn't, you know? (Diabetes Support Group, 26/09/01).

Participants' ambivalence towards SCR and 'therapeutic' uses of cloning techniques are related to broader social issues and examples. In particular, DM2 draws upon the terrorist attacks on the World Trade Centre in New York in order to illustrate his points (these events had taken place two weeks prior to the focus group). The inability of legislation and related policing to prevent terrorist attacks are used as cultural knowledge for articulating their views on SCR and cloning. At the same time, the inevitable slide down the slippery slope was not deemed a sufficiently persuasive argument for ceasing SCR. Participants' lived experiences of Diabetes were mobilised to legitimate their support for SCR.

In the cardiac support group, the potential benefits and risks of SCR were also central to the discussion. Informed by their experiences of medical experts, recent high-profile scientific controversies and other relevant experiential knowledge (including 'how society works'), participants debated how SCR and cloning-related research and applications might proceed, or otherwise. As part of these discussions CM1 adopted the role of 'devils advocate' by presenting a position that supported *both* reproductive and therapeutic forms of cloning. In doing so, the contributions of CM1 served to agitate other members of group and engender a lively discussion. However, as I will show, CM1's account of SCR and cloning exemplify how focus group discussions can illuminate public ambivalence, in particular, the perceived inefficacy of regulation and control are shown to generate public concerns.

During the first few minutes of the discussion, I asked participants what the role of the support group was, what their meetings usually included and whether they had thought or talked about cloning before? At this point, there were a number of small conversations taking place within the room and people were helping themselves to drinks. As these 'warming up' questions were coming to an end, CM1 steps in, stating:

CM1 About what you said [not clear who he is addressing], in all honesty the Government are dithering as usual. I think that this country will be overtaken fairly rapidly by others in this field. I mean, the Americans are gonna be ahead of us very soon, yet we started it. As usual we've got great ideas but somebody else makes money out of them.

SP So you think cloning is a great idea?

CM No.

CW2 Nooo, I don' think so.

CM1 I differ then. I think that there's a place for it. I'm not talking about full human cloning but I can see medical uses for cloning.

CM4 For organ replacement

CM1 Exactly (Cardiac Support Group, 18/07/01).

At this point in the discussion, CM1 indicates his clear support for 'medical uses' of cloning-related developments. Being at the forefront of scientific and medical developments is introduced as a matter of 'national pride', and Britain is pitted in competition with the USA in this modern 'space race'. As the discussion continues, however, CM1 begins to argue in favour of legalising *both* reproductive and therapeutic cloning within the UK (or at least it become unclear where he is 'drawing a line'). As the following set of excerpts illustrate, CM1 was quickly identified as the 'deviant' within the group which made for a rich and animated discussion:

CW2 You could see greedy people overstepping the line I think. I think it could get worse.

CM1 Well the beauty of it is if it's legalised ... [interrupted]

CM2 [Interrupting] You mean that the poor man's not gonna get it and the rich man is gonna get it?

CW2 Yes, that's exactly what I'm meaning

CM1 But if it was legalised at least they'd have a certain amount of self control.

CW2 No

[Talking over one another]

CW2 I'm glad you put it like that, that's exactly the way I meant it.

CM2 [Repeating himself] The rich get rich and the poor gets poorer.

CM4 If the Americans get in front of this thing there's a danger that they'll slap patents on everything and they'll charge money for everybody using these techniques and it's, I mean, I think it's just morally wrong.

CM1 Well?

CM4 That's my idea. It's morally wrong. You're a bloody wanker, you think money's the only thing

[Laughter]

CM1 No, no, no. The main problem is that the other side of the coin is there is nothing they can do about it. American and British systems are totally different. America is purely ... [interrupted]

CM4 [Interrupting] Commercial.

CM1 ... [continuing] it's a private economy.

CM4 Everything must make money.

CM1 Yes.

[Talking over one another]

CM1 By the same token it doesn't matter where you are, unless it makes money it's gonna fail. If it fails you'll get none of it. But there is no, utopia doesn't exist it never will. Therefore, money has got to come into it and money is the base-line for most things (Cardiac Support Group, 18/07/01).

In this exchange, the potential harms or risks are seen to arise from an abstract notion of 'money' - the commercial interests that are perceived to pervade scientific, medical and technological developments. Economic systems are expressed as a set of risks that are both faceless (as opposed to the 'mad scientist' rhetoric) and inevitable. That is, this area of research is being driven by the potential commercial gains. This suggests that there is a strong sense of powerlessness with respect to the commercial realisation of science and technology as well as regulation. Risks are perceived to extend beyond an identifiable group of individuals or even profession, but are attributed to wider societal structures and systems, and yet the 'greedy' or rogue scientist is simultaneously implicated.

Whilst acknowledging the presence of risks engendered by commercial interests, like FM2 (see section 6.2), CM1 seems to regard these risks as acceptable. Moreover, it is precisely because of the commercial vested interests in SCR and cloning that CM1 argues that both reproductive and therapeutic cloning should be legalised. Through legalising cloning, he argues, this area of research can be monitored and controlled:

CM1 Yes, but the question is, well I think the basis of the question is whether or not it [reproductive cloning] should be legalised or allowed? And the answer is, as far as I'm concerned, is it should be legalised otherwise we get folk doing it illegally for lots of money.

SP So if we were to legalise reproductive cloning, how do you envisage that working?

CM1 I've no idea [laughs]

SP I mean, you're saying that if we don't legalise it people are going to exploit it and they're gonna make money from it. I'm not sure I know what you mean.

CM1 I would suggest that it would have to be treated in the same way as the original abortion laws where you had to have a damn good reason for wanting it to be done. And to prove that reason other than on just economic grounds.

Following on from this, he goes on to say:

CM1 I'm still doubtful whether human [cloning] right true should ever be allowed, but I'm sure it will take place (Cardiac Support Group, 18/07/01).

As we can see above, CM1 argues that the potential for commercial exploitation is greater if reproductive cloning is practised as an illegal activity. Accordingly, through tight regulatory control both reproductive and therapeutic cloning could be developed within a *more* ethical framework (since he suggest that reproductive cloning is not entirely ethical) and certain risks, such as the commercial exploitation of SCR and cloning, could be minimised. One of the key factors for allowing both types of cloning is to enable the relevant science-base in the UK to develop as a world leader (especially in competition with the USA) and to allow for regulatory control rather than clandestine developments either in the UK or elsewhere – thus echoing the government perspective (see Chapter 3).

Whilst CM1 regards reproductive cloning as ethically problematic, 'ethics' are separated from 'practical' matters of regulation and control. In doing so, CM1 translates the social and ethical concerns – as identified by other participants – into regulatory issues. For instance, other members of the cardiac support group, in responding to what they saw as CM1's pro-cloning views, felt that the word 'cloning' evoked negative images and thoughts. As one woman said:

CW1 I mean, when you say clone you automatically think of somebody identical. I mean, you're not thinking that it's just a cell or an organ or something.

At this point in the discussion I asked whether they felt that it was more acceptable to talk about 'stem cell research':

CW2 Yes

CW1 No, no, no, no.

SP Why?

CW1 All you've really done is changed the name – it's still basically the same thing.

CM1 No, stem cell research is going to a certain point and stopping.

CW1 Aha.

CM1 And you're going to get somebody who will not stop, who'll go beyond that point. Now how are you going to control that? It's going to be impossible to control because who would know what they hell was going on? Erm, so therefore I would suggest that when the debate eventually takes place within the Government they are going to have to make up their mind one way or the other in total. So they've got to be all or nothing, and the trouble is it can't be nothing for the simple reason that it's already started and you can't go back on it. So you can't go back. It's there. And there's only one way to go and that's total.

CM4 Just sort of ... [interrupted]

CM1 [Interrupts] So, can you have a moral argument beyond that about how you actually control? I mean, I think that the legal argument has got to be that you've got to allow the research to take place. How you control it beyond that is a totally different question (Cardiac Support Group, 18/07/01).

On the one hand, CM1 contradicts CW2 in saying that SCR, or 'therapeutic' cloning, is separate to 'reproductive' cloning. On the other hand, CM1 seems to suggest that in legislative terms they are tightly interwoven and, therefore, must either be sanctioned or prohibited. However, inherent in CM1's view is a sense of powerlessness and fatalism – the cloning of human beings must be legalised because legislative bans are futile.

This position put forward by CM1 did not go unchallenged by others in the group. Whilst others agreed that it is difficult to prevent reproductive cloning and appealed to slippery slope narratives, sanctioning reproductive cloning was regarded to be as problematic as prohibiting medical uses of such techniques. For instance, one discussion that spun-off from CM1's comments related to the (in)efficacy of laws in preventing 'deviant' activities or behaviours:

CM4 [Addressing CM1] I think that you're thinking along the lines of the difficulty of controlling it. It's just you're saying that legally it would be difficult to control, you know. Heroin addiction is impossible to control but do you think that we should legalised it?

CM1 No.

CW1 No, but with heroin and all that, it's all self-inflicted so.

CM1 That is self-inflicted yes.

[Shouting over one another]

CM1 Follow your [CM4] line of argument, cannabis is illegal in this country but you go across to Holland and you can buy it in the corner shop.

CW2 Are you sure that this tape is gonna be long enough [laughing]?

SP Yep, I've got another one

CW2 Good, 'cause once we get started.

[Laughter]

CM1 Abortion in this country is legal, it's illegal in Ireland and so they come across here. The same thing. I mean no matter what area you look at, the world is getting smaller daily. It's globalisation for everything.

CM4 The difficulty of controlling something is not a good reason for legalising it.

CM1 Alright then, but the only way you can do that is if you've got one law covering the whole world and we don't have and never will have. Because if you outlaw it here, somebody else will say I can make money out of this and we'll make it legal there. And it might be somewhere like Cambodia.

CM4 You're looking at it this way with a bankers mind. You keep coming back to money all the time.

[Laughter]

CM4 I mean, I would never have given money a thought in talking about this. I don't think money comes into it. Money is totally immoral when you apply it to something like this.

CW1 Not for the research it's not.

CM1 Money is the bottom line for the research – that's the problem (Cardiac Support Group, 18/07/01).

In having one participant within the group taking what was seen to be an 'extreme' position on the topic of SCR and cloning, provided a focus for the discussion. As this exchange illustrates, the efficacy of laws to prevent reproductive cloning is questioned by drawing parallels with other issues – recreational drugs and abortion. These issues are also mobilised in order to illustrate that we can no longer think about science regulation as a local concern because the UK is no longer understood as a bounded nation state. CM1 reconfigures his view of 'local' regulations for SCR and cloning in relation to its connections with a global order, for instance, people can develop cloning in other countries and 'consumers' can travel receive treatments or purchase such services.

In addition to the use of cultural knowledge and resources when constructing their views on cloning, it is also interesting to note the significance of participants' situated knowledge. As a retired banker, CM1 applies his knowledge and experiences of business and planning to the SCR and cloning context. Others in the group are reflexively aware of the role of CM1 in drawing their attention to financial dimensions of the scientific enterprise, which, as evident above, is responded to with great humour along with, at times, exasperation. Such data illustrates the role of social location in shaping people's views of SCR and cloning. It is reflects positively on the appropriateness of focus groups for allowing participants to bring a range of experiences and knowledges to the discussion, generating their own questions and issues according to their own terms of reference.

6.4 Publics' Views on Science-Public Relations: Trust Transparency and Uncertainty

In the following section, I will explore how participants reflect upon science-public relations, including the cognitive authority of science, the nature of the scientific enterprise and their view of scientists. As I will show, we need to investigate the public understanding of science-in-general that underpins public ambivalence towards SCR and cloning. Participants' reflections of the wider issues of science in contemporary society are then linked to specific issues that relate to the particular areas of research in question, as the accounts of participants switched between 'science-in-particular' and 'science-in-general' throughout the discussions. From this, however, I can also explore some of the wider issues around expertise, trust and risk that are central to cPUS approaches.

In keeping with Beck's theories of reflexive modernity and risk, discussions within patient support groups revealed that participants have recognised a shift in science-public relations. There is a reflexive awareness of the decline in scientific authority and the growth of alternative sources of expertise. This growing scepticism towards the scientific enterprise is largely attributed to public conflicts between a range of people vying for expertise. As the following quote from the Huntington's Disease support group illustrates, participants reflected upon increased public mistrust towards science and the implications of this for the relationship between science and the public:

> HW Even in the supermarkets now, you don't buy ordinary vegetables now, you go over and buy that because they're pure and all the rest of it and there's nothing scientific in it, nothing in it – the grounds clear and they haven't been sprayed with stuff. That's only a small thing but yes I do think that it's growing.

And all this destroying GM crops and all that, I do think there's a nucleus and it is just beginning to spread. Maybe we get more information now, the general public, and because of that we know that all scientists are not good. Maybe that's the problem, whereas a few years ago people didn't realise that. And we know that with Huntington's there have been cases who have held back information that would, well maybe not with Huntington's but with other degenerative disorders, they've held back information from other scientists throughout the world because they wanted to be the first, they wanted to get the money. So I think that has probably put people's, made people aware that not all scientists are white.

HW5 I'm not saying that some of the things aren't deplorable but of the change that they make, or say they make are over exaggerated. For example the tobacco companies, I think that the anti-smoking lobbies are just as dirty, just as a for instance.

HW I think the thing about anti-science is that people are much more, they've got costs involved and there's huge cost implications for scientists taking the ball and running with that. We've just heard about effect of BSE on sheep, people are worrying about these threats that have been going for about five years or so. The money is huge.

HW TV programmes and that now, you get folk coming on and telling you that herbal remedies, I mean that's really coming to the fore now. And washing your hair instead of buying shampoo in what you can make. You can make your own shampoo, "it's cleaner and it's better" and it's all this sort of thing. There's a lot of that and there's a lot of this thing. People are of course, we're more informed now. Twenty years ago we weren't informed about anything, we just took what they said and believed it. You believed whatever your doctor told you and that was it. But now there's information and things going about.

HW I think if you just look back over the last ten years, how many things have we been told that are really really bad for us and then five years later they come back and say oh it's quite all right? And if you'd eaten more fat you're gonna die of cancer and you know. And then you're told if you eat too low fat a diet then you will get something else. I think that people now are a bit more aware that scientists are not Gods (Huntington's Disease Support Group, 31/10/01).

In this exchange – which took place towards the end of the group discussion – we can see participants' awareness of a range of conflicting voices within science as well as the emergence of alternative forms of expertise outwith the traditional walls of expert systems. A key dimension to this discussion is the lack of trust in all experts regardless of whether they are seen to represent traditional science institutions or competing ones. Science and scientific activities are not seen as value-free but instead are inherently social – and, importantly, 'the public' 'know' this. It is difficult to know, from this matieral, whether any expert knowledge is allocated a privileged status over others or whether, indeed Beck is correct in suggesting that there has been a 'return of uncertainty to society ... [where] ... no one ... or everyone is an expert' (1994: 8-9; also see section 4.3).

In slipping between the topics of organic vegetables, GM crops, smoking, BSE, shampoo and cancer, participants construct their own identities in relation to a range of others. What this seems to suggest is that the proliferation of expertises has engendered a situation where expert-public relations are 'played out through the processes of consumption' (Michael, 1998: 320). To this extent, the public come to scientific expertise in a similar way as they do other aspects of consumer culture and in doing so, blur the boundaries between 'citizen' and 'consumer'. The point here is that the identity of the consumer lends itself as set of discourses through which publics can locate themselves vis-à-vis an increasing number of expert knowledges and positions.

The above excerpt from the focus group with the Huntington's Disease support group indicates how matters of expertise, trust, transparency and (un)certainty are interwoven. Recent controversies such as BSE/v-CJD have contributed to the paradox where publics are both more trusting and sceptical of science and scientists. A number of participants across the focus groups and interviews raised concerns about transparency and effective communication, reflecting upon whether disclosure of information by scientists is indicative of trustworthy science. For instance, in the cardiac support group, CM1 questioned whether scientists are providing all of the relevant information:

> CM1 The thing about the whole concept [of cloning] is that it has been brought into the public domain and we are talking about it like we are at this present time. I would hate to think what is going on behind closed doors which we have not even got an inkling of. And it could possibly be way beyond this little lot (Cardiac Support Group, 18/07/01).

Similarly, within the Huntington's Disease support group, participants question the trustworthiness of scientists in communicating their work to the public:

> HW And we know that with Huntington's there have been cases who have held back information that would, well maybe not with Huntington's but with other degenerative disorders. They've held back information from other scientists throughout the world because they wanted to be the first, they wanted to get the money. So I think that has probably put peoples', made people aware that not all scientists are white (Huntington's Disease Support Group, 31/10/01).

Both quotes indicate the inherent contradictions in the shift towards transparency and openness in science noted in Chapter 4, Section 4.5. As Brown and Michael have outlined, the increase in information available to the public has had the 'effect of making people more aware of the

complexities of science – that science does not speak with one uniform and necessarily coherent voice' (Brown, 2002; see also Brown and Michael, 2002). Moreover, publics' awareness of the social and political nature of scientific research, such as scientists' professional aspirations, means that scientists' attempts to 'tell it as it is' can reinforce existing levels of mistrust and uncertainty.

As the critical approach to PUS reveals, publics' trust in science and scientists cannot be limited to people's understanding of medical science and scientists but must be related to the wider social and political worlds in which people locate both themselves and the scientific enterprise. For instance, participants within the cardiac support group, reflected upon the public debates on SCR and cloning in both the media and Parliament. The parliamentary debates on SCR and cloning were regarded with scepticism, primarily because politicians were not to be trusted. Participants were also critical of media accounts of the issues because they believed that the quality of debates was poor. The following excerpt is taken from a discussion which took place towards the end of the focus group with members of the cardiac support group. Here, participants reflected on their experiences of the focus group vis-à-vis the wider public debates, and prompted the group to think about wider issues of science-public relations and public inclusion in policy debates:

> CW1 Do you think that they should have more larger scale debates, not the Government, but for common people like us?
>
> CM1 Well there are ten of us here and ten different viewpoints.
>
> CW2 Oh yes.
>
> CM1 If you enlarge that by a thousand.
>
> CW1 Yes, but even if you want to get it over to people. You've got to get it over someway haven't you and get them on your side of whatever?
>
> CM4 Everyone that you spoke to would need to have the ability to absorb that knowledge and understanding and that's not possible.
>
> CW2 No.
>
> CM1 No the layman hasn't got sufficient knowledge to give an answer to them.
>
> CW1 Well they'd only start off, well, you see all these television programmes, debates, or they just have an audience that walk up being on it. They have other things, they had it about a woman being a lesbian or gays. You know, it draws your attention to it. Whether you turn it on by accident or you hear something. Well, obviously there might be some things where I say, 'I'm not gonna watch

that' and turn over. And it's like oh, the wee argument starts or they're doing their points of view and the doctor or whoever's interviewing there, and you'll think oh that was good this week so I'll watch it. Just a build up that's what I'm meaning. I'm not saying that the Usher Hall with all these people in because nobody would talk.

CM4 Yeah, but these programmes can engineer the result of the debates because it's an invited audience.

CM1 It's not only that ... [interrupted]

CW1 There's always other viewers outside on the outside of the television and it's bringing it to their attention. It's to get them to start to think.

CM1 The situation like that, the person that's interviewing them asks the questions, in such a way as to get the desired answer.

CM4 Yep, yep.

CM1 There are two ways to ask the same question. One will get the answer 'yes', and the other will get the answer 'no'.

CW1 Yes, but, as she [SP] asked us when we first came in tonight, 'have we thought about it, have we talked about it?'. No. She got us talking about it. Whatever view it is, you're talking about, you're still talking about it. It's bringing it to our attention. That's what I'm getting at – it's not enough people (Cardiac Support Group, 18/07/01).

In this exchange members had conflicting views. Some believed that there needed to be wider coverage of the SCR and cloning issues within the media in order to raise awareness and to generate public discussions. Others were sceptical of media debates which were regarded as staged and limited the scope of debate. Participants were also reflexive about the range of views within the cardiac support group and considered the implications of this for implementing large-scale public debates, with the suggestion that public debate would require an educational component to it. Such arguments echo the claims put forward by Wynne and others who are critical of PUS models and present communication and engagement practices between scientists and publics (see Chapter 4).

Participants in the cardiac support group then raised concerns about parliamentary debates on SCR and cloning:

CM4 Political discussions, I mean, politicians are professional manipulators of the truth.

CM1 Without a doubt. I mean, that's one of the problems in many senses – it's [SCR and cloning] not been discussed.

> CM4 They never tell the bloody truth, they don't know what it means. The whole topic of cloning has already been raised and has been fairly widely debated in the media but the powers that be have made it such a low priority it's either on the back page, oh no, we cannot do the back page that's the sport [laughs]. It's either in the middle of the paper or it's on about two o'clock in the morning on channel 17 (Cardiac Support Group, 18/07/01).

When scientists are perceived to be linked to politics, participants are highly sceptical towards the views expressed and evidence provided. Such scepticism also emerged within discussions with other patient group members. For instance, during the interview with one of the Alzheimer's carers she talked about the range of information sources such as broadsheet newspapers, tabloids and medical journals such as the Lancet (which she said she regarded as very trustworthy), for obtaining information about scientific and medical issues. I then asked her how she felt about scientists:

> AC2W I trust some scientists. I mean, you know, like Susan Greenfield, but it's when like the Government scientists, they've got such a bad reputation and they deserve it (Alzheimer's Carer 2, 03/10/01).

This suggests that when the science/politics boundary is perceived to have been breached, credibility and trust diminishes. Scientists, like politicians, are seen to push forward a particular viewpoint based upon vested political interests. However, within the above accounts there is an interesting contradiction. On the one hand the scientists, the media and politicians were believed to have a responsibility to communicate with the public (which was sometimes constructed as 'educating' the public). On the other hand, communication and public engagement activities are understood as marred by attempt to manipulate, mislead and delimit public views.

6.5 Patients as Active Citizens: How Patients Assert Experience-Based Expertise

Following on from the above discussion, I will consider the extent to which participants in the patient support groups are actively engaging with and redefining their relationship with experts, and constituting themselves *as* experts. In considering the applicability of theories of reflexive modernisation to the SCR and cloning debates, I will explore any insight participants' views and understandings of the science-public relations offer into transformations of 'patient' identity. For instance, theories of reflexive modernisation suggest that risks generated by 'expert institutions', such as those associated with SCR and cloning, also engender lay ambivalence towards the cognitive authority of science and scientific expertise. As publics become more aware of 'risks' they simultaneously become aware of the choices which exist in daily life, and

new forms of social agency emerge (see, for example, Irwin, 1995). In turn, scientists are increasingly aware of 'public' ambivalence and the growth of alternative forms of expertise, including 'experience-based expertise' (see Chapter 4 and Section 5.6.2). It is, therefore, important to consider how publics construct their own identities – especially as experts in their own healthcare matters – and see their role within public debates.

Commenting on science-public relations – or more specifically relations between scientists, clinicians and people who are 'genetically at risk' from Huntington's Disease – Novas and Rose have argued that 'patients' actively engage with experts (2000; see also Michael, 1998: 321-323).[4] Through an analysis of the risks generated by new molecular genetics, Novas and Rose argue that those who are genetically at risk are actively formulating life strategies and new forms of personhood. The rise of 'genetic risks' are shown to have induced 'new and active relations to oneself and one's future' (Novas and Rose, 2000: 785). Central to these new forms of personhood, are transformations in expert-patient relations where patients are reconstituting the role of scientists and clinicians and enrolling them into their own new life strategies. As Novas and Rose have argued, 'patients' and their families are,

> increasingly demanding control over the practices linked to their own health, seeking multiple forms of expert and non-expert advice in devising their life strategies, and asking of medics that they act as the servants and not the masters of this process. These persons defined by genetic disease have an investment in scientists fulfilling their promises and discovering the basis of, and the cure of treatment for, genetic conditions (2000: 490).

Thus, developments in medical genetics are seen to produce ideas about genetic identity and in turn, *creates* new subjects. And this emergent subject is one who 'is to become skilled, prudent and active ... elements in the practice of cure' (Novas and Rose, 2000: 489).

This account of expert-patient relations is reminiscent of Beck's theories of reflexive modernity where risks generated by science, technology and medicine bring about new 'expertises'. Developments in human genetics are argued to have created new 'knowledge' of the human body (e.g. around health and illness) and, in turn, created novel forms of patient identities. Comparing Novas and Rose's analysis of Huntington's patients with my analysis of patient groups in the SCR and cloning debates, does suggest that some participants are constituting

[4] 'Patients', here, is used as a generic term for including those who have already been diagnosed with Huntington's Disease, people who have had received a negative test result and those who have not been genetic tested for whatever reason. Thus, 'patients' covers both those who are 'ill' and 'asymptomatically ill' who are defined by genetic disease (see Novas and Rose, 2000).

themselves as active citizens in their own healthcare regimes. For instance, within both the Huntington's and Diabetes support groups, participants indicated that some members attend conferences and public events relating to scientific and medical developments. Relevant information from these events is then conveyed to other members of the group who could not attend. And whilst such explicit knowledge-seeking activities was not common across or within groups (i.e., some members *seemed* to be more active than others), membership of a patient support group can be interpreted as the presence of the 'active subject' (Novas and Rose, 2000).[5] Participants indicated that membership of patient support groups provides emotional and social support, along with information relevant to their healthcare needs and a forum to discuss science and medical developments towards treatments and cures. For example, support group meetings were said to have included invited speakers, such as clinicians and medical researchers, as well as used for discussing their experiences as patients, family members of patients or carers.[6]

In a number of focus group discussions and interviews, participants indicated that one motivation for contributing to my research was to learn more about SCR and cloning developments and the potential implications for their own or other families members' medical treatments. For instance, in the Sister-led fertility support group, F2W3 was interested to know whether SCR would develop organs to be transplanted. Similarly, F2W1 wanted to know more about the potential treatments for Huntington's Disease – as this was something that affected her grandfather and, now, her brother. However, to suggest that an interest in medical treatments was the only motivation would be overly simplistic. Others, such as one Alzheimer's carer, declared an interest in the moral and ethical dimensions of SCR and cloning:

> AC1M It was topical if I remember correctly. At the time that the letter came there was stuff in the press which I had sort of read without being avidly interested. You can't read everything in the papers but I found the moral question fascinating without having sat down and thought deeply about it. Just

[5] I do not mean to suggest that attendance at science meetings is the only or most important indication of the presence of the 'active subject'. The constitution of the active subject can be achieved through a range of actions in both public and private spheres, such as attending patient group meetings, searching the Internet or simply talking to friends and colleagues.

[6] There are two number of points of clarification to make here. Firstly, only the Diabetes, Huntington's and Alzheimer's support groups were linked to larger, national patient organisations. The two fertility groups and cardiac support group were not officially attached to national patient organisations, but were locally run. Secondly, the cardiac support group differed to all other groups to the extent that their meetings were organised as social gatherings, such as playing skittles, quiz nights, going on a dinner cruise and having massages. As CM1 says, 'The group has evolved into something that's basically social. Other heart groups have gone a different route, they went for stupid things like exercise' (Cardiac Support Group, 18/07/01).

> superficially my reaction was that there are moral issues or ethical issues, serious ones (Alzheimer's Carer 1, 21/09/01).

Similarly, the second Alzheimer's carer, within the same sentence as stating that she was interested to know more about the potential medical applications of SCR and cloning, also declared an interest in the moral dilemma's generated by such research:

> AC2W I have a sister who has early onset dementia. We're now in a very bad phase. This is exactly the sort of thing, cancer, Alzheimer's, etc., etc., that this is going to help. My first words were now what sort of check, what sort of holds are there going to be on just doing your own thing? What, it's not control it's the ethical borderline. How are you going to keep checks on that and nobody abuses it? (Alzheimer's Carer 2, 03/10/01).

Both quotes illustrate that these participants were interested to find out about the potential medical applications of SCR and cloning and yet took a critical stance. The promise of medical treatments for their respective family members did not preclude concerns regarding the ethical issues generated by these developments. What is seen to be at stake in SCR and cloning developments goes beyond health care benefits but also includes a broader unease about the risks that may ensue. The offer to participate in this research can be seen to have facilitated an active engagement with the issues by members of patient group support groups and providing a forum within which they could explore their views.

This active engagement with relevant health care research was also a key issue for those in the Diabetes support group. Members of the group described themselves as an 'extremely active branch' who attended relevant meetings and showed a keen interest in the latest developments for understanding and treating Diabetes. As with members of all support groups that contributed to this research, during the discussion it was evident that their participation was as much to do with expressing their views as seeking information about SCR and cloning and potential medical applications. One participant in the Diabetes support group had prepared for the focus group by searching the internet and printing a transcript of an interview with Ian Wilmut. And as the discussion developed it became clear that this member was unhappy with the lack of information that he had received from the national Diabetes patient organisation. When I asked whether he was concerned about this he responded, 'Yes I suppose it does because this has been the first chance that I've had of airing my viewpoint and saying that I'm for research of this type' (DM2, Diabetes Support Group, 26/09/01). Active engagement for DM2 involved a combination of seeking information from a range of sources as well as feeding back into the patient organisation and relevant experts.

As we saw in the previous chapters, patient groups have been characterised by eSCR advocates as demanding developments in stem cell and cloning-related therapies (see 3.4 and 5.6.2). Patients are enrolled as actors in the pro-eSCR lobby, and the overlap of interests between 'patients' and core-eSCR-scientists are highlighted (i.e., to develop treatments and cures). Such strategies of enrolment tend to be reinforced by human interest stories and corresponding emotional discourses (see Brown and Michael, 2002). Rather than simply rejecting this position, we should note that within the patient group discussions a number of participants echoed similar views. As the following excerpt from the Diabetes support group discussion illustrates, patients reflect upon their health status and articulate a set of expectations:

> DW1 I think that anything that helps people who have chronic illness can only be for the good. ... If only that technique had been around to stop that [husband dying of Diabetes] then that would have been wonderful. I could only wish for people who are in that position.
>
> DM2 That I think is very much an informed comment. Going back to what I said earlier, if you put these questions to the general public you tend to get an affirmative answer for cloning and reproductive research from people who have been affected somewhere in the family, by chronic disease. But, other people who have healthy families and who never had a day off work in their lives quite often don't see the necessity or the requirement for it.

DM2 then goes on to say:

> DM2 Well I'm certainly demanding it. It's great. It's going to come too late too help me, but if it comes soon enough to help the kids that are growing up just now with [Diabetes] then so much the better. ... Not only to help Diabetes ... but to help people with Parkinson's, MND, etc., etc. I think that if it's going to help people at the end of the way then it should be followed up.
>
> DW1 And if it'll help people with spinal injuries when you see so many horrific cases then that would be wonderful (Diabetes Support Group, 26/09/01).

Such sentiments were also stated within other groups discussions. Participants in the Huntington's focus group discussed issues relating to the possible sources of stem cells. When talking about the use of adult stem cells from aborted foetuses one woman stated:

> HW2 I would not agree with a foetus being aborted simply to help somebody with Huntington's. But if a foetus is going to be destroyed anyway, surely it's far better to do some good for somebody else. I mean, I think this is the difference for somebody who's got children at risk and somebody who's not got anybody at risk [from Huntington's] and maybe could look at it a little more objectively. But I've got no problem with it.

And then later on:

> HW Like we've said, if you've got somebody, you know, you've got someone in the family, your grandchildren and things like that with the possibility that they might develop Huntington's and all that then you know, I think it's worthwhile (Huntington's Disease Support Group, 31/10/01).

The above quotes are typical examples of the kinds of statements made within all patient focus groups. Contained within the above are a number of pertinent points that should be teased out. Running through these accounts are aspects of the constitution of patient identity according to 'experience-based expertise' (see Collins and Evan, 2002). In a similar vein to that of the scientists, participants in the patient support groups also appealed to their embodied and lived experiences of particular diseases for articulating their support for the development of stem cell therapies. Significantly, patients separated their 'expert' identities from the wider public who were considered to lack such experiences and by extension, expertise. To this extent we might say that these examples illustrate how patients are actively constituting another layer of expertise; that is, their own 'expert' identities which is based upon experiential knowledge and embodied biographies.

The constitution of patients as experts often involved patients reflecting upon various aspects of expert systems and their relationship to it and, importantly, *within* it. That is, patients acquire knowledge of relevant healthcare services and systems and actively insert themselves – with their expectations, hopes and fears – into the network. For instance, AC1M, an Alzheimer's carer, talked about the advice, support and treatment available to his wife who has early-onset dementia. He discussed the various problems that he and his wife encountered in receiving adequate healthcare treatment and, in particular, the drawn-out process of being accurately diagnosed. As this excerpt shows, upon learning through his daughter that there was a history of dementia in his wife's family, AC1M conveyed his suspicions that his wife was also developing early-onset dementia to their GP:

> Of course the family didn't advertise "the family disease" as I now know they refer to [re: Alzheimer's]. But [my wife] had always been afraid that she would get it and when the early signs came she was very upset. I pooh-poohed it to her face and said "there's no reason to believe that it's hereditary". Of course I know that that was a silly thing to say. I was absolutely wrong. But I did tell the doctor and he pooh-poohed it, just completely pooh-poohed it ... And eventually last year after about three long letters [written to the GP] – which I don't know if he read – documenting everything. And eventually, eventually after I first mentioned my fears he referred her. That was last summer ... three years from when I first used the words Alzheimer's to the doctor. Three bloody years (Alzheimer's Carer 1, 21/09/01).

In the context of this part of our discussion AC1M articulated a number of instances where he felt that medical experts had failed, of which the above example was the one. Other problems identified were the administrative system at the hospital (a part-time secretary had forgotten to send out the hospital appointment), existing therapies (there was only a 50% chance that the drugs would slow down the deterioration) and social support networks (a role fulfilled by the Alzheimer's Society).

In connection with his experiences of the failure of experts, AC1M went on to talk about medical research into dementia. Problematic expert-patient relations were not confined to the more obvious patient requirements, such as diagnosis, access to specialist clinicians and treatment, but were also extended to include patients' involvement in what he called 'experimental therapy' and clinical trials:

> AC1 And yet no-one, to my surprise, no-one has sought to involve us in any research or anything. It kind of surprises me. I would have thought that someone so young with teenage children and all the rest of it, I would have thought that all the research from different angles, your one [SCR] and I had a lady who lives in Edinburgh, but some researchers have come along, well two, one the basis of the Alzheimer's Society giving out my name, which I've said they can do. But no-one on the social side of things ... no-one from the social angle, the medical angle, the physical - if there's a difference - you know, my wife's stability, no-one. Not even a questionnaire to fill in except in relation to the assessment of my wife. I've filled in countless questionnaires of that sort but that's in her medical files, nothing to do with research ... which is surprising (Alzheimer's Carer 1, 21/09/01).

He then comes back to this point when reflecting upon the development of stem cell therapies:

> The time will come, after all processes have been gone through and approvals and all the rest of it, the time will come when that's going to be used experimentally or in trials, or whatever the terminology is, on humans. Would one want, would I want my wife to be a guinea pig? That answer is yes because I can't see it could make things worse in any practical sense. And if it could help, well, there's not much to be lost. If you come back to stem cell research, yes it's got to be speeded up if there is a real prospect that this will transform treatment or be really effective, perhaps more effective. I'm not saying there shouldn't be research on the drugs and all the rest of it, but every avenue has got to be explored. And I think that the stem cell one, going back to the point I was rambling about earlier, the fact that it has such wide application, potentially, yes it should be speeded up. And I'm talking from the scientific, medical point of view. Leaving aside the ethical question. If it can work, get on with it would be my reaction. Lives are being destroyed and devastated right now and if politicians have the real measure of that, I'm not suggesting I do - I'm only talking about my personal experience. I don't know how many people are

> affected and how badly by all of these things. I can imagine it's an awful lot, a much bigger number than I imagined and it happened to me and I began to think about it (Alzheimer's Carer 1, 21/09/01).

The excerpts above can be seen as 'points of connection' (Giddens, 1990: 88) between patients and expert systems (in the GP's clinic and the hospital). AC1M's account illustrates how different types of expertises are often negotiated in what we might call the micro-politics of expert relations. For instance, the GP's diagnosis and treatment was not accepted as correct and his status as expert was disputed. Instead, embodied and experiential accounts of AC1M and family (including his wife and daughter) constitute expert knowledge that usurps that of the traditional expert. In this reconfiguration of expert-patient relations, patients are not simply consumers of science, technology and medicine, waiting around for new developments, but instead are active throughout a number of aspects of relevant healthcare systems. Participation in clinical trials can be taken as one other component to the fashioning of new forms of responsibility and obligation to contribute to the production of new therapies and ones own treatment.

6.6 Conclusions

The overall aim of this chapter has been to show how the accounts of patient support group members 'open up' the SCR and cloning debates. In particular I have shown that it is overly simplistic to characterise 'patients' as wholly supporting developments in this area. Whilst none of the participants within the focus groups objected to SCR and cloning for developing medical therapies, they held complex and contradictory views that are more ambivalent than the parliamentary debates or core-eSCR-scientists' accounts have indicated. People's understanding of SCR and cloning is located within their existing knowledge and experiences of science and scientists, of the efficacy of regulation and the wider social context. To this extent, and in keeping with theories of reflexive modernity and risk society, it does appear that people are both credulous and critical of science and scientific expertise.

Most of the participants could not be described as scientifically or technically knowledgeable about SCR and cloning practices. As already stated, the majority of people had not thought about SCR and cloning or made connections between these developments and their own healthcare practices. What this chapter has shown (and will continue to develop in the following two chapters), however, is that it is not necessary for publics to hold 'scientific knowledge' in order to apprehend the range of issues pertinent to the subject matter. Although the focus group and one-to-one discussions being the first time that most people had considered and

discussed their views, participants were able to formulate ideas and generate discussions on the basis of to their own frameworks of knowledge. That is, they brought a range of social and cultural 'knowledges', including embodied and lived experiences, to the discussion.

In the focus group context, the range of knowledges brought 'to the table' by individuals served to raise issues that were marginalised by core-eSCR-scientists' discourses and in the parliamentary debates. For instance, within the cardiac support group, the retired banker, CM1, introduced issues relating to the economic factors and commercial interests involved in SCR and cloning. The group then considered topics such as patenting, differences between the UK and US economies, and the role of regulation in balancing ethical and commercial issues. That people draw on their views and experiences of wider social, political, economic and cultural domains, was further exemplified in the Diabetes support group discussion where participants connected SCR and cloning with eugenics. As a form of cultural knowledge, eugenics serves as resource for articulating a particular set of shared values for defining the limits of 'ethical' scientific practices. That is, what constitutes acceptable, or ethical, scientific practice is understood as culturally and historically contingent. To this extent, members of the Diabetes support group (as with a number of members in other groups) underline the difficulties in distinguishing between acceptable and unacceptable scientific practices (see Kerr *et al.*, 1998a). Here, narratives of the slippery slope are based upon knowledge of how science and society 'work'. Such accounts also reveal that, science and society are not distinct, monolithic categories by people in these patient support groups, but are shifting and mutually constitutive.

In such ways, the boundary between science and society was problematised in focus group discussions. Moreover, participants were quite reflexive about the inherent uncertainties and contingencies of the scientific enterprise. For instance, within the Huntington's Disease support group participants moved away from uncritical constructions of scientific knowledge – as (re)produced in scientists' accounts – to an account that acknowledges the contingencies and, often, transient nature of what constitutes scientific 'knowledge'. As shown in section 6.4, a range of examples were used for illustrating how science is multi-vocal and that publics must interpret these voices and make choices about how to live.

Running through many of the participants' accounts are issues of trust. The cognitive authority of scientists can no longer be taken for granted, as participants reflect upon recent science controversies such as BSE. Such controversies have raised an awareness, not only of the inherent uncertainties in science and the provisional nature of scientific 'knowledge', but also that scientists are not a homogenous group. For instance, members of the Huntington's Disease

support group talked about 'good' and 'bad' scientists, and AC2W discussed how some scientists could be trusted (e.g. Susan Greenfield) whilst others could not (e.g. Government scientists). Discussion about the trustworthiness of scientists, therefore, illustrates how 'trust' in scientists' expertise was intimately linked to participants' view of science and scientists as connected to related expert systems. For example, for some people within the cardiac support group, scientific claims made via the media and politicians were regarded with scepticism. This shows that scepticism is equally applied to 'experts' in other social spheres, such as the media and politics.

This chapter confirms cPUS arguments of a need to understand publics' views of SCR and cloning as shaped by and reflecting the embodied experiences and social location of participants. On the one hand participants within the patient support groups were in favour of developing stem cell therapies with a number expressing an interest in participating in clinical trials. On the other hand, we cannot 'read off' people's views of SCR and cloning from their status as 'Diabetics' or 'infertile. As I have shown, contrary to the core-eSCR-accounts, people with such conditions express complex and ambivalent views and adopt critical positions towards this area of research. Participants' active engagement with the issues raised by SCR and cloning illustrate how, as Edwards has argued 'they apprehend innovation through what they already know, and produce new meanings and understandings which are not always predictable' (2002: 324).

CHAPTER VII

(Re)Constructing Embryos: A Comparison of Fertility and Patient Support Groups

7.1 Conceptualising Embryos as Flexible Actors

This chapter builds upon the issues raised in chapter six. Continuing to highlight people's ambivalence towards SCR and cloning, I will focus upon the ways in which embodied biographies and experiential knowledge shape views of using human embryos for this area of research. At the same time, I will reflect upon how developments in SCR and cloning are feeding back into and reconfiguring people's understandings of embryos and of life. In this regard, this chapter is an analysis of the co-construction of science, technology and society through the lens of eSCR.

As already discussed in previous chapters (see Section 3.3), there has been a return to the 'embryo question' in the SCR and cloning debates. The announcement of Dolly the cloned sheep in 1997 and of the development of the first embryonic stem cell cultures by James Thompson in 1998 (Thompson et al. 1998) generated a great deal of public debate within the UK. As the debates progressed (e.g. within Parliament, newly established working groups and the media), it became evident that the use of embryos for SCR extended beyond existing regulations on the use of embryos for research purposes – as contained with the HFE Act. That is, the original 1990 HFE Act regulated the use of human embryos for research in the area of reproductive medicine, whereas eSCR involves the use of embryos for a potentially wide range of medical research areas, including regenerative medicine and drug development. This expansion of the uses of human embryos in biomedical research has reopened the complex legal, moral, ethical and social issues relating to embryo research. Moreover, such research problematises the teleology of the embryo that places it within a sequential, linear narrative of 'life'. By this, I mean that the teleology of the embryo can no longer be represented as gametes-embryo-foetus-baby. As new actors are introduced into the narrative (e.g., stem cells and patient groups), the meaning of embryos are further pluralised. To this extent – and as I have shown in chapter 3 – the SCR and cloning-related debates constitute the most recent embryo controversy and must be located within the lineage of previous debates on this topic.

My conceptualisation of embryos as flexible signifiers is not novel, but is indebted to a number of writers, especially within the broad field of feminist studies of new reproductive technologies (see, for example, Cussins, 1998a, 1998b, 1998c; Franklin, 1997; Goslinga-Roy, 2000; Morgan and Michaels, 1999; Spallone, 1989). Such works on the variability of meanings attached to the embryo have already attended to its multiple constructions and roles across a number of sites, including politics, religion, popular culture, science and medicine. In investigating scientific and medical interventions into human reproduction across history (e.g. abortion, pre-natal screening, IVF, embryo research and pre-implantation genetic diagnosis), feminists have offered astute analyses of the corresponding range of ideologies, narratives, forms of representation and embodied understandings of embryos (see, for instance, Martin, 1996, Duden, 1999, Morgan and Michaels, 1999). In particular, the construction of the embryo according to 'scientific facts' has been criticised by a number of writers who have attempted to denaturalise such meanings and reveal their contingencies (see for example Duden, 1999, Franklin, 1998). Furthermore, 'scientific' accounts of embryos are shown to eclipse both women's bodies (as 'sources' of embryos) and the lived, embodied understandings of those undergoing fertility treatments (see Franklin, 1998; Morgan and Michaels, 1999). For instance, how people constitute relationships between themselves and embryos or how embryos move between 'identities' as objects, kin, potential lives, biological material and so on.

The significance of this existing body of work to my own research is that it provides a conceptual framework for reflecting upon the material-semiotic practices that 'bring to life' human embryos. In particular, embryos are revealed as the outcome of a complex network of actors and practices, such as the discursive construction of the 'pre-embryo' in the embryo debates (see Mulkay, 1997; Spallone, 1987, 1989), material-semiotic practices within the fertility clinic that seek to classify the embryo and render it visible (see Cussins, 1996, Franklin and Roberts, 2001) and the embodied experiences of women undergoing fertility treatments (see Franklin, 1997; Goslinga-Roy, 2000; Rapp, 1999).[1] By this connection, the embryo – which Franklin has called one of the 'new biologicals' (2001b: 303)[2] – must be understood as always in a state of becoming rather than being. The 'identity' of embryos, then, are subject to interpretation and can defamiliarise or denaturalise existing categories of personhood, kinship and even the role of biological 'facts' (see Franklin, 2001; Strathern, 1992).

---

[1] This list is not an exhaustive list of actors and practices or of relevant research in the area, rather it is indicative of some of the readings that have informed my analytical and conceptual approach for understanding the 'embryo' in the SCR and cloning debates.

[2] The 'new biologicals' is used by Franklin when referring to new entities created by material-semiotic practices within contemporary biological sciences that defamiliarise our understanding of 'what it is to do biology or be biological' (2001b: 303). Other examples include transgenic animals, genetically modified seeds and patented gene sequences.

To return to the case in hand, in building upon analyses of the 1980's embryo debates (see, for example, Franklin 1997, 1999; Mulkay 1993, 1994, 1997; Spallone, 1986, 1989), my own analysis of the 2000/2001 SCR and cloning debates within Parliament has shown that there remains little consensus on the meaning of human embryos (see chapter 3). Instead, human embryos continue to represent different things to different commentators. For instance, my analysis of scientists' accounts illustrates how we cannot talk of a single scientific and technical understanding of the embryo, but that within science there are disputes over where one can 'draw the line' between acceptable and unacceptable uses of human embryos (see chapter 5). Despite these controversies over the use of embryos for SCR and cloning-related developments in the parliamentary debates and scientists' accounts, however, the experiences and views of those undergoing fertility treatment and potential user-groups (patient groups) are grossly underrepresented. Or to put it another way, these groups are grossly overrepresented by politicians, scientists and other spokespersons (e.g. the Genetics Interest Group or public relations officers from patient charities) but they themselves are not present. That is, patients are strategically invoked and their views represented. This can be attributed, I would argue, to the dominant framing of the SCR and cloning debates whose lineage can be traced back through the embryo debates of the 1980s to the abortion debates which have been sporadic since 1967. Here, the embryo question continues to be polarised according to pro-eSCR (who were also pro-abortion/IVF/embryonic research) and anti-eSCR advocates (who were anti-abortion/IVF/embryonic research).

This dichotomous framing of the debates has, I believe, acted to simplify many of the issues involved in the use of embryos, and to construct particular associations between different actors in this sociotechnical network. For example, 'couples' undergoing fertility treatment are recruited by pro-eSCR-advocates as 'on their side' and repositioned as embryo donors (see section 3.5). Similarly, potential user groups and their families are recruited as 'desperate' and as having an instrumental relationship to the embryo (see section 3.4). In this sense, the relationship between embryos, potential user-groups and those undergoing fertility treatment remains unproblematised and unexplored. This chapter focuses upon the various ways in which members of the fertility and patient support groups construct their relationship to the embryo. Building upon existing analyses of the meanings of embryos, I will explore how people talk about embryos, how they are understood in relation to cells and foetuses, how embryos can and cannot be used, their processes of production (i.e. in the context of assisted conception practices), how they are visualised and what cultural resources are brought to bear upon their constitution. In doing so, I will show how the relationship between scientists, clinicians, those

undergoing fertility treatment, patients (as potential-users) and embryos, are far from simple. Instead, the embryo appears in contradictory ways and also serves as a vehicle for understanding and making sense of the relationship between experts and publics, as well as those undergoing fertility treatment and potential user groups. Indeed, in keeping with the general vein of this chapter as a whole, I will argue that addressing the embryo question helps us see how the relationship between experts and publics is becoming increasingly complex, where the boundaries between these groups are often blurred.

7.2 A Note on Methodology and Structure

When preparing for the group interviews with fertility support groups, I had envisaged the members as having already thought through the issues of embryo donation for medical research. I had assumed that they were aware of the potential use of embryos for SCR, even if they had not fully considered their views on this. In the event, however, the majority of participants in the patient-led support group and all of those in the Sister-led support group appeared to come to the focus group without having any well-formulated views on either embryo donation or SCR. The focus group discussion was an opportunity for participants to explore their views on this area, which involved asking many questions of one another and myself. Also, given my own limited knowledge of the use of embryos in reproductive medicine and SCR at the time of the interview, I was often unable to convey technical or procedural information. Since the aim of my research was not to 'test' participants technical knowledge of SCR and related issues, their views should be regarded as no less significant than if they possessed such 'technical' knowledge. Instead these accounts are analysed in the spirit of cPUS, focussing upon the ways in which those interviewed make sense of and represent SCR and cloning-related developments. Accordingly, the analysis reveals the complexities and contradictions of their views and how they are embedded in wider cultural assumptions and embodied experiences.

At the beginning of each focus group I introduced my area of interest and outlined why I wanted to speak to them and why their views are important. This involved telling a 'story' about SCR and cloning-related developments, which included the use of both embryos and adult tissue for research, the use of the cell nuclear replacement technique (aka therapeutic cloning) and the potential medical treatments and therapies that may ensue. When telling this 'story' to the fertility support groups I highlighted their potential role in this research as embryo donors; in the focus groups and one-to-one interviews with the patient groups I highlighted the range of diseases for which SCR and cloning-related developments may provide treatments. Thus, in line with the parliamentary debates, my 'version' of the SCR and cloning debates also invokes

members of patient groups as key actors in these developments. For instance, when introducing myself and my research at the beginning of each interview or focus group, I also appealed to the teleology of the stem cell 'story' - from embryo donation, to the scientists conducting eSCR to potential patient groups – which is also reflected in my methodology (since these are the groups that I have included in my research design). And in doing so, I opened up the discussions to include the issue of embryo donation so as to capture the range of views on this within and across the groups.

The following two sections in this chapter (7.3 and 7.4) revolve around the views of participants within the patient-led and the Sister-led fertility support groups. Sections 7.5 and 7.6 is a discussion of the negotiation over meanings of embryos in the patient support groups. Whilst there are some interesting convergences between the groups, I have separated them for the purposes of clarity. Where relevant I have endeavoured to draw comparisons and distinctions between different perspectives.

7.3 Donating 'Spare' Embryos for Research Purposes: Meanings and Uses

Within official documents (e.g. Department of Health's report, June 2000) and scientists' accounts of eSCR (see chapter 5), the embryos used for research purposes are referred to as 'spare' or 'surplus' embryos from IVF cycles (see for example House of Lords Select Committee on Stem Cell Research, 2002). That is, 'couples' undergoing IVF are 'invited' to donate 'spare' embryos that will not be used for implantation specifically for research purposes which may include eSCR. However, what constitutes 'spare' or 'surplus' embryos and the practices involved in their production is never clarified. For instance, it is not made clear that scientists require embryos that are graded as 'viable' for implanting into a woman in order to derive 'healthy' stem cells.[3] Stem cells cannot be derived from embryos which are graded as 'poor quality' and would not be used for implanting into a woman. Thus, the language of 'spare' and 'surplus to requirement' is central to processes for shifting our understanding of embryos from potential life to biological material used for medical research. At the same time, however, the potential life of embryos are implicitly recognised in legislation, where they continue to be afforded a 'special status' requiring legal protection. This, illustrates how embryos are subject to a number of constructions where not all embryos are regarded as the same (see Franklin and Roberts, 2001).

[3] Indeed, we should note that one research institute within the UK has, at the point of writing, received over 1500 'spare' embryos from a fertility clinic and is yet to produce a stem cell line.

The extension of the UK regulations to allow the use of human embryos for SCR, makes it important to explore the views of people undergoing fertility treatment on donating their 'spare' embryos for medical research. At the time of designing and conducting fieldwork (2000-2001), 'potential embryo donors' were excluded from the dominant debates and it was because of this that I chose to include such groups in my research. Since the amendment to the 1990 HFE Act in 2001 it seems that pro-eSCR-scientists are now acknowledging this as an area for legitimate concern. In this section, then I will address the views of those undergoing fertility treatment on donating embryos for medical research in general, as well as for the specific purposes of SCR. Alongside this, I will consider the views of participants in the patient support groups – again whose views on this subject remain unexplored in the policy process.

For those undergoing fertility treatment, the prospect of donating 'viable' embryos for medical research generated a great deal of unease. Whilst a number of people from the fertility support groups had already agreed to donate 'spare' embryos for medical research, these embryos were understood to be 'non-viable' (i.e., could not develop into a baby). This is captured in the following quote from M1 in the patient-led fertility support group:

> F1M1 We've had to sign every time we've done a fresh cycle. We have to decide at the start what's going to happen during that cycle. So you're allowed to keep it for five years, allowed to perish, or the extra ones that you wouldn't have used are allowed to go for research purposes – that's the three. But by saying that they're allowed to go for medical research, well, the understanding there is that, well, my perception is that they wouldn't have progressed anyway so they're not any use to us. So then they can be split, the cells can be examined to see how they're developing, how they're splitting and things like that. But you appreciate that that's to help couples in the same position as yourself (Patient-led Fertility Support Group, 19/06/01).

What F1M1 seems to suggest is that he was happy to donate embryos when they were used to help people requiring fertility treatment rather than for other forms of medical research. However, he assumes that only non-viable embryos are used for medical research rather than viable ones. Within the Sister-led fertility support group, participants were also reluctant to donate viable embryos for research purposes:

> F2W1 I wouldn't give them away. They're really precious to me unless there was something wrong with them and they weren't any good to me. And then I would give them to research, but certainly no give them [sic].
>
> SP Have you agreed at any point to donate your spare embryos for research?

F2W1 I've agreed to donate eggs, but obviously I couldn't do that anymore but previously I have. And it was because there was something wrong with them, because they weren't any good to me.

F2W4 One of the things that we do here, erm, is embryos, only if they are not good enough for taking or transferring [inaudible] but patients would have to sign a consent form for that. So [inaudible] or may have been. If you leave them in the incubator for long enough they may be good enough to grow stem cells from.

F2W2 On the form after a certain amount of time, if they're not being used then they can be used for research?

F2W1 But if you have good ones and you choose them first, what happens to the other ones?

F2W4 If they are good enough they will be frozen. The ones who are not good enough to be frozen will not thaw anyway, so there's no point. [Inaudible] put them in the incubator and if they survive for another couple of days then you get stem cells (Sister-led Fertility Support Group, 27/06/01).

Both of these accounts of embryo donation for medical research illustrate participants' understanding of which embryos would be made available for research purposes. After undergoing the processes of classification, embryos are no longer regarded in any homogenous sense (if they ever were) but instead come to mean different things. Those classified as 'non-viable' – that is, they could not be used for reproductive purposes – are not viewed as 'precious' in the same way as those that could result in a pregnancy.

In the above excerpt, it is also interesting to note that the intervention of the Sister (F2W4) 'explaining' that the embryos used for research are not 'viable', added a different dimension to the patient-led support group. Her presence as an 'expert' within the group served to legitimate clinical practices and so to alter the direction of the discussion.[4] Whereas in the patient-led group the participants discussed the issues around embryo donation for medical research at length, within the Sister-led group the Sisters' contribution limited these discussions by rendering them irrelevant. After the above intervention of the Sister, both F1 and F3 stated that they were happy to donate their 'spare' embryos for research purposes.

So, returning to the first quote from the patient-led fertility support group, F1M1 outlines two key points. Firstly, his understanding of embryo donation is that only non-viable embryos would be made available for research purposes. Secondly, 'spare' embryos donated from fertility

[4] I have since learned that only viable embryos are required for creating stem cell lines rather than non-viable ones. During the focus group, however, neither myself or the other participants knew that the information provided by the Sister was incorrect.

treatment are envisaged as being used in research within the field of reproductive medicine only – to improve understanding of and treatments for infertility. In order to press M1 on his views of the purposes of embryo research and the implications of this for his willingness to donate embryos, I sketched an outline of the original 1990 HFEA regulations for embryo research and the 2001 amendments, before raising the question of donating embryos for SCR:

> SP Do you feel any differently about donating embryos for stem cell research than you would if it was for within reproductive medicine? Does this throw up any new concerns for you?
>
> F1M2 From my point of view any embryos that we get erm, I presume that by having the embryos, that they are viable, therefore, I want to keep them for my own treatment. Not for somebody else to do research on – as much as in a way that you would also like to be able to contribute because how do people learn? How do they, the doctors learn how to inject ICSI cycles, or whatever, unless they've got something? But then I believe they use erm, egg cells or just eggs for that which is slightly different from [interrupted]
>
> F1M1 Part of the bit that you take for research is for that, because we were at [another hospital] it was a new angle that was explained to us that that part of that research is to train people to be able to inject the sperm into the egg and they have to be able to do that to get the qualifications. We've always ticked that box on the understanding that it's for that aim, it's always for infertility.
>
> F1W3 We understood that it was just eggs that haven't fertilised for medical research, it wasn't actually embryos. I just ticked that and said if the eggs haven't fertilised then you can have it, because it's not good and you can use it for whatever. But it wasn't an embryo. No way are they getting any of my embryos if I get any. [laughs]
>
> F1M1 We've agreed that any embryos that are going to be allowed to perish can be used. It's for the infertility side of things, you know, we haven't thought outwith that – that it could now go to cloning.
>
> F1W1 If we were to tick our box that says yes it can go for medical research, does that mean then that it can go to any research? (Patient-led fertility support group, 19/06/01).

Throughout this exchange, participants share with one another what they understand they are consenting to when donating embryos for medical research, in terms of 'what' are they donating, what they will be used for and why embryos are required for research purposes. Given that the participants cited above were all undergoing fertility treatment and were yet to have a child (only M4 within the patient-led support group had already had a child through fertility treatment), it is not surprising that 'viable' embryos were regarded as valuable entities and imbued with hope and expectation. As in Franklin and Roberts' analysis of the construction of embryos in the clinic during PGD programmes (2001), the accounts of those interviewed as part

of my research reiterates how 'viable embryos' are centred whereas 'non-viable' embryos are peripheral to fertility treatment.

As these accounts seem to suggest, for those undergoing fertility treatment 'spare' embryos are those that *could not* be used for reproductive purposes. This understanding is also extended to include eggs – those that did not fuse with the sperm to create an embryo were set apart from viable eggs that went on to develop into embryos, and yet aligned with non-viable embryos. According to the views of those above, then, the processes of ordering, classifying and grading gametes and embryos by 'experts' within the clinics has profound implications on the relationship between people undergoing fertility treatment and their embryos. People undergoing fertility treatment, like scientists, appeal to technical descriptions of some embryos. This use of a scientistic understanding of embryos illustrates the extent to which hegemonic meanings attached to embryos have permeated the ways in which we think about embryos. As in the accounts of pro-eSCR-scientists and eSCR-advocates in parliament, the complex medical processes and interventions for producing eggs and creating embryos are absent from the accounts of those undergoing fertility treatment. Here, the scientific and medical means of categorisation for ordering and assigning particular meanings to gametes and embryos are privileged.

Exceptions to the above, however, did occur within the patient-led fertility support group. During the discussion there was one couple who sat quietly for most of the discussion. Whilst they did not offer their opinions directly, they demonstrated that they were engaged in the discussion through their body language, such as nodding or shaking their heads at appropriate points. After approximately one hour their body language seemed to suggest that they were unsettled by some of the discussion, especially as the discussion moved on to consider issues around donating embryos for SCR and cloning-related developments. At one point (approximately three-quarters of the way through the focus group) I asked whether they would be happy to donate embryos for SCR and directed my gaze towards the said couple. The female partners' response was a very quick and sharp 'No', and when I asked why she explained:

> F1W4 Because it's an embryo and it's like my baby, it could be my baby. I can't bear the thought of you cutting it up and doing whatever you want to do with it. I can't bear the thought of that.

And then others followed on:

F1W1 That's the difficultly that probably everyone here has to get over. It's a chance. And for us to give that away to somebody else just to play with is taking away our chances.

F1M3 We've got to go through a lot to get that.

And then later in the discussion:

F1M3 Everybody here tries very very hard to get enough stock whether they be good grades or not good grades (Patient-led Fertility Support Group, 19/06/01).

In these excerpts, participants allude to a more embodied understanding of embryos that are tightly bound up with the pain (both emotional and physical), hope and expectations involved when undergoing fertility treatments. To attach utilitarian meanings to embryos, was interpreted as objectifying not only embryos (as potential babies) but also the couples undergoing treatment who have made personal investments in the processes that they are undergoing (see also Cussins, 1996). A number of studies, such as Cussins (1996), Franklin (1993), McNeil (1993) and Price (1999) have shown how fertility treatment tends to be framed according to narratives of hope which tie women to motherhood, offering a technical fix to complex social and biological problems. Therefore, to introduce a view of embryos as sources of stem cells rather than potential children, is inconsistent with and disrupts narratives of hope.

The tension that arises from the construction of embryos according to grading processes, where some are deemed as potential lives and yet others are regarded as less precious was lucidly presented by M1 in the patient-led fertility support group. In drawing upon his own experiences and those of others who have been members of the support group, he explains his own views of embryos vis-à-vis 'life':

F1M1 I personally don't have any worries if it's for research on infertility. If it's an embryo we've had the right grading of embryo to go back and one that doesn't look like it will make the grade and will be allowed to perish, I've never had any problem with that going to research. I think that for me that's because after so many years every one that goes back [into the woman's womb] has either the possibility of going on to develop or perish. And at the outset, I know it sounds very harsh for me to take this line, but it's, I've always seen it as the opportunity for life at that stage at the outset. I've never particularly allowed myself to get wrapped up in saying that it's a child at that point. Because at that point to me it's not, it's the possibility of life at that stage. It's not a human being. That's maybe sounds harsh and I fully understand people who say that from the point of conception an embryo as it starts to divide that is life and I can fully understand that. I don't see that as wrong at all. But for me, as time has gone on, has always been the opportunity of life and if it's not gone, as we've

had for five years of not having a child, then that possibility of life didn't take off. But it wasn't at that stage a child, it was always just a, it was cells that offered the possibility of life. And as I say, for five years it hasn't. So I think that because there's so much upset and there's so much emotions involved and you can see how it's quite a difficult thing to kind of hang on. For some people what could be their potential child [pause], have I gone away from what we were saying? There's different perceptions. It's so emotive, I've seen it from all the couples that have passed through the group. They all have different perceptions, it's all emotion, and quite rightly. Every one of the embryos that's produced whether it's going to ultimately perish naturally within the woman or if it's good enough graded at the moment for us, one, two, three the grades that they do, if it's not going to make the grade at that stage and go back then that one that's allowed to perish I've always just said it offered the opportunity of life and just left it at that. I've never let myself get emotionally caught up with it. I don't know whether that's just the way I've tackled it (Patient-led Fertility Support Group, 19/06/01).

In this account, the embryo is something that is worked on in a number of ways – not only in its 'production' and grading by clinicians, but also requiring emotional work to distinguish embryos as cells from embryos as a potential life. And given that even those embryos graded as 'potential life' have not resulted in a full-term pregnancy for M1 and his partner, then 'viable' embryos continue to be imbued with potent meanings. In this sense then, such views illustrate how scientised distinctions between embryos according to their 'quality' are problematic even when they appear to be adopted by 'couples' undergoing fertility treatment.

I also asked participants in the Sister-led fertility support group how they feel about viable embryos compared to those that are graded as non-viable. Since this focus group took place after the patient-led group, I drew upon some of the themes that emerged within that group, one of which was the differing degrees of emotion attachment to 'different' embryos. As in the patient-led group, participants distinguished between embryos according to their grading. But in addition to this, one participant raised the issue of the quantity of embryos created through fertility treatment:

F2W1 How do you get emotionally attached to one embryo if you've got seven or eight there? It's a difficult thing to say because I've been through quite a lot up here erm, if it doesn't work then how can you be attached to something that you've not got? Alright, you've seen the wee cell in the camera but it's not going to materialise into anything so why get emotionally involved with something that's never going to be?

F2W3 I got emotionally involved with the two that have been put back inside

F2W1 That's right.

F2W3 But not the ones that haven't. If it's not meant to be, if it's not meant to happen. What's important, what you're concerned about is what's going on in here, not what's going on in the ones that didn't work.

F2W3 then goes on to recount her experiences of a recent failed cycle of treatment where two eggs were successfully fertilised and graded as viable:

F2W3 The guy came through from the lab to say that they'd been successfully fertilised and – my husband and I do not actually have IVF we do ICSI – and that they'd managed to get two eggs and that both eggs had been fertilised and was alive. And that's the first time that anybody has ever said that word to me, that they were alive. I went home that night and I thought my God, they were alive. And when I came back in and only one of them had survived and the way I felt about that one was far different than any of the other cycles that I've ever gone through, purely because he had used the word 'alive'. It's a whole rollercoaster of emotions, far more than any of the other cycles because I'd never thought about it in that sense before (Sister-led Fertility Support Group, 27/06/01)

Here, as in the previous accounts of embryos, the material-semiotic practices within the clinic that constitute some embryos as viable and others as non-viable has as a powerful effect upon the perceived relationship of people to embryos. The distinction between embryos is further strengthened, from the perspective of F2W3, by the subsequent language used by the clinicians to describe 'viable' embryos as 'alive'. Additionally, the description of emotional attachment to embryos 'put back' into the womb reveals how understanding of embryos has powerful embodied dimensions – dimensions that remain unexplored in the accounts of core-scientists and other SCR advocates.

At the time when the focus groups were conducted, the people whose views have been discussed so far in this section were childless. And as I have already suggested, this seems to have had some impact upon their views of embryos and embryo donation for medical research. One of the participants in the patient-led fertility group, however, already had one child through using fertility treatments (with his wife who was absent from the focus group discussion). At the point when we met, he and his wife had decided that they were unlikely to continue with fertility treatments to conceive a second child and were now faced with the issue of what to do with the remaining 'viable' embryos that were being stored. As this excerpt shows, whilst he is happy to donate them for medical research he wants them to only be used in research that would help other people requiring fertility treatment:

F1M3 We knew, well, me personally, I can't speak for my wife, but these five embryos in storage are a possibility of life, you know, as far as I was concerned.

If they were going towards helping in any way instead of perishing, helping other infertile couples then I would be quite happy for them to go down that road. Actually, the proviso being that it'd be helping infertile couples. Can I do that? You know, I don't really know.

F1W2 responded to the thoughts of F1M3:

F1W2 With them going to help other infertile couples you know, in a way you know there'd maybe be some hope of life. But by going to medical research there may be a bit of distrust there because you just don't know what's going to happen.

Then, later on in the discussion they return to this issue:

F1M3 In four years time they'll contact me and we'll decide by that time yes we're not going to go ahead [with further fertility treatment]. I would like these embryos to go to treating infertility or helping people treat infertility, not for any other purposes because that was the reason that we came in the first place. But I don't know how much say I have in that if any of course.

F1W2 But when you say that, I mean, to treat infertility, do you mean to be transplanted into a woman or for research?

F1M3 Personally - and I can't speak for my wife, my wife might speak differently - I would donate them.

F1W2 And they could be used for either?

F1M3 I haven't really thought about it to be honest.

F1W2 Because that's something that I keep thinking about. Be careful with, you know, be specific.

F1M3 Yeah, no no, I don't know is the answer.

F1W2 I mean, when it comes to the time it's my mistrust though. If you write something and you didn't mean to say it, you know, so simply and it gets used for anything.

F1M3 Yeah well, you get that (Patient-led Fertility Support Group, 19/06/01).

In this exchange it is not entirely clear what F1M3 means when he talks about embryos helping infertile couples. Even when quizzed by F1W2 on whether he means that they could be used for implantation into another woman (other than his partner) to allow another couple to have a child or whether he means only to be used for research into furthering our understanding of infertility and for developing therapies - he does not offer a conclusive response. However, what is evident is that he wants his donated embryos to be used within the field of reproductive

medicine rather than SCR, which was seen to extend outwith the remit within which their embryos had been produced.

As indicated in the above exchange between F1W2 and F1M3 in the patient-led fertility support group, the concerns of F1W2 regarding donating embryos for medical research went beyond the issues of using them for research into infertility compared to regenerative medicine, but lay with a sense of uncertainty of what would happen to embryos used for research. The decision of whether to donate embryos elicited fundamental questions relating to the trustworthiness of scientists and medical researchers to tell people what they are using embryos for. In the following exchange, participants share their doubts on the trustworthiness of scientists:

> F1W2 I mean, why would you want to give embryos if you don't have the knowledge of what they're going to do with them, you know?
>
> SP Well if a scientist was going to come to speak to you, they would tell you that they were going to take – if you offered them your spare embryos – they would cultivate from your embryos stem cells. Cells that they would then use to grow particular tissue, say if they were to try and grow skin, nerves, heart cells and so on.
>
> F1W2 I don't know. I've still got a mistrust when I fill in forms about what things they're really gonna be used for. There's just a general, I'm still not confident that they're going to be used for what they say they're gonna be used for.
>
> F1M3 Well Dolly the sheep didn't turn up until she was alive.
>
> F1M1 Well yeah, that was my earlier point. Dolly the sheep never turned up until she was alive.
>
> F1M3 There's also the other situation of babies organs in the Liverpool hospital where people were dissecting their organs without permission from the parents (Patient-led Fertility Support Group, 19/06/01).

As a novel and unknown area of research the use of embryos for SCR produced a number of anxieties and fears which were anchored around a sense of mistrust in scientists. This exchange demonstrates how participants construct a lineage of issues, slipping between SCR, reproductive cloning and the illicit retention of organs in hospitals. The general sense of mistrust offered by F1W2, was furnished with two grounded examples by F1M1 and F1M3. And whilst I do not believe that these three issues were understood as the 'same thing', such an exchange does demonstrate how people draw parallels with a range of issues when formulating their thoughts on novel and controversial developments. At the point when this discussion took place a number of high-profile 'organ retention' scandals, including the Alderhey Hospital, were

receiving a great deal of media attention. During these 'scandals' children's organs were either used for medical research, or simply 'retained' without the consent of the parents, thus generating anxieties and mistrust in official procedures for gaining consent from next of kin.

The examples of Dolly and the organ retention cases are used to elaborate on participants' anxieties over how their embryos have been and continue to be used by scientific and medical researchers. Such examples seem to bear out Wynne's argument that public perceptions of what constitutes a risk may be more ambiguous than a normative framework for analysing risks allows (2002). For instance, in the above account of embryo research, the examples used by the speakers serve to convey a sense of unanticipated risks – what Wynne calls 'unknown unknowns'. This is further captured by M2:

> F1M2 Can I use an example here? Dolly the sheep was born in 1997. Nobody knew about Dolly the sheep until 1997. I'd have signed these forms four years ago, in 1996, or five years ago, whatever, my viewpoint might have been different once I knew the cloning side of Dolly the sheep. But I signed that form not knowing what people could be, well, not people could be cloned but sheep could be cloned (Patient-led Fertility Support Group, 19/06/01).

What was seen as the 'secret' development of reproductive cloning has generated concerns regarding what is being done behind closed doors in the laboratory. In this sense, F1M2 is concerned that potential embryo donors do not have access to all of the relevant information regarding what their embryos are being used for and could be used for in the future. The insertion of both Dolly and Alderhey into the narratives of embryo donation, I would argue, reveals a pervading sense of powerlessness on the part of the public over the direction of scientific and medical research (see Kerr *et al.*, 1998a, 1998b).

In the patient-led fertility support group, one participant located her sense of mistrust and powerless within the context of her experiences of fertility treatment. As shown on the previous page, F1W2 expressed some strong concerns about what happens to embryos donated by people undergoing fertility treatments and at one point compares scientists working on eSCR to Burke and Hare. During the discussion she describes her experiences on being asked to participate in a new drugs trial as part of her fertility treatment. At the end of the focus group I offered to provide a copy of the transcript to anybody wanting one and so agreed to send a number of copies to the group co-ordinator who would forward them on to other members. Two months later I received a letter from F1W2, who, after reflecting upon her contributions to the group discussion requested that I replace the part where she discussed the drugs trial with the following explanation:

> F1W2 When asked to take part in a research study [clinical trial], the way that the study is explained and presented and the length of time given to think about it has a marked effect on the way I approach the study. If I feel rushed and not given more than a couple of days to think about my involvement, then I may develop strong and conflicting emotions through both a perceived moral obligation to take part and frustration at not having sufficient time to think it through carefully. Time to talk to others, both those going through a similar situation and professionals in the field, may help to alleviate any fears that have developed and may make me feel more confident about making an informed decision (Personal correspondence, 29/08/01).

In the letter she wanted to make it clear that her concerns about this drugs trial were no reflection of her view of staff at the hospital which she and her partner attends; 'I have nothing but admiration and respect for them'. The source of her sense of mistrust was, instead, attributed to 'scientists testing these drugs, people whom I will never meet and for whom I'm simply a statistic'. For the purposes of my analysis, this illustrates how, when participants talk about distrusting scientists, what appears to be a general statement may obscure more nuanced views of science and scientists. And whilst a number of quantitative studies have been commissioned to examine the extent to which the public trusts (or otherwise) scientists and other experts (see, for example, *The Public Consultation on Developments in the Biosciences*, 1999), what these fail to do is to explore how trust is not fixed across time and how 'scientists' as a group of experts are not homogenised (see Chapter 6). As the example of F1W2 in the patient-led fertility group suggests, mis/trust may be temporary and contextual, and as much to do with ones immediate knowledge of scientists in order to humanise our image of some scientists where others remain abstract.

The general consensus within the patient-led fertility support group seemed to be that they were not willing to donate 'viable' embryos for SCR (and, in fact, it was not clear that they were willing to donate non-viable embryos for this purpose either). In this context, one of the participants – F1M2 – reflected upon the implications of this upon scientists working in the field of eSCR. Specifically, F1M2 was concerned that if the scientists didn't receive enough embryos then they would turn to alternative sources:

> F1M2 I would also be worried about the encouragement of perhaps third world countries, scientists in Britain, for example, willing to pay perhaps normally fertile, erm, couples for embryos for money. Because as well, erm, what ethics are there in place to cover that? I mean, we've got problems of, you know, the embryos we want to keep for ourselves but these people need to be able to do the research and if they pay for it you know, it's, it becomes a market place (Patient-led Fertility Support Group, 19/06/01).

According to this view, people undergoing fertility treatment are caught in a double-bind: either they can donate their 'spare' embryos for research that they are not entirely comfortable with, or they refuse and then scientists will exploit other 'couples' in countries with less regulatory controls. Thus, in considering the range of unanticipated consequences that might arise from SCR developments, F1M2 reflects upon the potential 'risks' that may arise if people like himself do not make their 'spare' embryos available for this research.

7.4 Consent: A Question of Trust?

Running through the discussions of embryo donation was the issue of consent and, intimately related to this, questions of risk and trust. As alluded to in much of the discussion in this section so far, how consent is obtained is seen as problematic by those undergoing fertility treatment. Within the patient-led fertility support group in particular, members raised concerns about the procedures in the clinic for obtaining consent from patients to donate embryos for research purposes. Discussions regarding the perceived inevitability of reproductive cloning led on to issues relating to the source of embryos and their potential uses. As one of the women within the group asked, 'But the big question is where do they get their healthy cells?' (F1W2) to which another responded, 'Do you have to have an embryo?' (F1W1). When one participant confirmed that embryos are used for this research, this sparked a lively exchange of views with everybody talking at once – which is itself indicative of the emotive nature of using embryos for this area of research. As the initial clamour to talk died down it became clear that the issue of consent had emerged as their primary concern:

> F1W2 Well that's what I've been thinking. Every time you go into hospital and you sign your, you read all the consent sheets. We live in a culture of reading the small print, eh? You're always looking for something where you're going to fall and sign something and going to go through the net. That's the kind of culture we live in, yeah. It breeds fear for me this word "cloning" if there's not legislation there, not proper permission sought and given. Of course some people are going to give permission but if there's not proper legislation there and it's not done properly that'll be my biggest fear, you know, taking without people knowing (Patient-led Fertility Support Group, 19/06/01).

Her understanding of the broader social, political and economic context can be seen to have informed F1W2's perception of the consent procedures, where the issue of 'consent' and 'knowing' was seen as problematic. Despite the use of consent forms – which in some senses are indicative of a move towards transparency and choice rather than the more paternalistic doctor-patient relations of old – the problem of trust is not resolved for F1W2. In particular, she points to several problematic areas in the consent process: what information is offered to

the patient, how it is presented and, as indicated in the letter that she sent (see above), how much time people are given to consider their position.

Many joined in the discussion about obtaining and giving consent within the fertility clinic context, offering their own thoughts and experiences:

> F1M3 Can anyone, what I was trying to think of earlier on, can anyone remember when they started with treatment, remember filling in the forms. It was a few years ago when my wife and I filled in this form. And I remember, we both had to sign I think it was two different forms, the husband or partner had to fill one and the other filled in another. I remember we signed everything and you're under a great amount of stress, you know, as we're all well aware of here, a hell of an amount of stress. We were ticking boxes and I was thinking this and my wife was thinking that. To this day actually I cannot remember, I just remember saying to my wife, "oh it says here, what do you want done with any frozen embryos? Do you wish 'A', that they go to medical research, or whatever". Well that's three years ago and I cannot remember what the form even looks like now, because I was under a hell of a lot of stress. Can anyone else remember?
>
> F1W2 Yeah, it says that they will be stored for up to five years and then after that you have to pay after that, and then after that you can keep them longer with consultation with the doctor ... [interrupted]
>
> F1W1 You can keep them for up to ten years I think
>
> F1W2 ... [continuing] But it doesn't say what happens after that, are they allowed to perish is it?
>
> [People talking over one another]
>
> F1W2 Yeah it doesn't say what happens to them.
>
> F1M2 The thing you're talking about is that to be used for the treatment of the partner, one for other medical or scientific research and I can't remember what the other one is
>
> F1M1 Allowed to perish
>
> F1M2 Allowed to perish, yes I think it was those three, those little boxes.
>
> F1W2 What happens after they're allowed to perish?
>
> F1M1 They will just wither, the cells will just degenerate and become nothing.
>
> F1M3 Well I can't even actually remember if ...
>
> [F1M1 and F1M3 talking over each other]
>
> F1M3 ... the dilemma we had, sorry [to F1M1], was whether to sign, for instead of letting them perish letting them go to medical research and I

> remember thinking for quite a while about that one question. It's interesting that none of us can remember word for word what was on that form. Am I right in saying that? Yeah?
>
> [General agreement and confirmation within group]
> (Patient-led fertility support group, 19/06/01)

This excerpt from the discussion illustrates the problems that are confronted, from the perspective of potential embryo donors, when obtaining consent. The situational context within the clinic when consent is obtained was seen as stressful and confusing, and in this sense not conducive for thinking through ones views on embryo donation for medical research. In addition to this, when I reflect upon many of the accounts outlined above, there is an implicit sense of a moral obligation to participate in medical research – especially when understood as contributing to research on human reproduction. For instance, F1W2 (from the patient-led fertility support group) introduces this within her letter to me and F1M2 (also from the patient-led fertility support group) talks about the importance of donating eggs so that clinicians can be trained to perform ICSI.

7.5 Distinguishing Embryos from Foetuses

Within the diabetes support group discussion, participants considered what kinds of arguments might be used against the development of eSCR and cloning-related developments. Here, they identified faith-based arguments which stipulate that 'God's creations should never be touched' as the main source of anti-eSCR claims (DM2, Diabetes Support Group, 26/09/01). In reflecting on how some faith communities may feel about the use of embryos for research purposes, DM1 argued that other sources of human materials such as blood or bone marrow were seen as 'probably more acceptable' (DM1). I then asked the group to consider why they think that for some people it is more problematic to use embryos than other forms of human tissue for SCR:

> DW2 Well, as (DM2) says, I think behind it, the problem of religious belief. You know, they are cutting up something. I mean God created a person, you're interfering with God. I mean, that's the way that some people would look at it. Religion I think is behind it.

At this point, DM2 introduced into the discussion an article written by Ian Wilmut from the Rosin Institute that he had obtained on the Internet. From this article, he read out a small extract to the group:

DM2 If I can just now read you a research piece by Ian Wilmut of the Roslin Institute, which you'll know is near here, erm, about the making of human stem cells for treating various conditions. "Stem cells matched to the individual patient could be made by creating an embryo by nuclear transfer just for that purpose using one of the patients cells as the donor and a human egg as the recipient. The embryo would be allowed to develop only to the stage needed to separate and culture stem cells from it." And this is the important bit. "At that point an embryo has only a few hundred cells and they have not started to differentiate. In particular the nervous system has not begun to develop so the embryo has no means of feeling pain of sensing the environment." (Diabetes Support Group, 26/09/01).

As we have already seen in chapters 3 and 5, Wilmut's account of pre-14-day embryos is in keeping with the dominant rhetoric of pro-embryo research advocates that emerged during the embryo debates of the 1980s. When DM2 introduces Wilmut's 'description' of eSCR he is using it in the context that it was originally mobilised during the embryo debates – to invalidate religious and moral opposition to the use of human embryos by framing the issues according to scientific and technical 'facts' (see Mulkay 1997).

The constructions of the pre-14-day embryo as a group of cells, as shown above, tends to simultaneously frame the issues in ways that eclipse the lived and embodied experiences of the women and men from whom they came. It is, therefore, significant that in the diabetes support group DW1 responded to the above description by locating the embryo within the experiences of men and women:

DW1 I wonder how many women would be against the embryo being used as against men? I think that would be quite an interesting thing.

SP Why do you think there might be a difference?

DW1 I really don't know. But I suspect that more women might think that, you know? It wouldn't worry me at all, but I suppose of course there's an emotional bond. I don't know, I'm just surmising.

DW2 I think the maternal side comes into that (Diabetes Support Group, 26/09/01).

In this account, then, DW1 and DW2 mobilise an embodied accounts of ones relationship with embryos in order to differentiate between men and women's understanding of embryo research. Implicit in this argument is an understanding of women as mothers, nurturers and carers whose relationship to embryos (and by implication, foetuses and children) is determined by their biological capacity to bear children. That is, women form emotional bonds with embryos and for men, perhaps, less so.

Again, in countering this suggestion, DM2 returns to the scientific description of embryos:

> DM2 Bearing in mind you would only, well, I doubt you'd be able to see this with the eye. You'd be able to see it under the microscope. Do you think you could have an emotional attachment to something that was the size of a pinhead? That was just ... [interrupted]
>
> DW1 No I suppose not, no. I'm thinking of an embryo.
>
> DM2 ... [continuing] that was just literally? No you wouldn't have any physical embryo, something that you could take out and bury or anything like that.

As DM2 was talking he was holding up one of the articles that had a picture of a human blastocyst similar to that used by Austin Smith (see Chapter 5, Section 5.2) in order to illustrate his point. This argument (combined with the image of the pre-14-day embryo) had a powerful effect upon the view of people within the Diabetes support group. The discussion that ensued illustrates the extent to which DM2's intervention resulted in participants re-examining their own views of embryos:

> DW1 It would be, you know, in some ways it's maybe picky but people have this misconception of the embryo as being something that is alive. If there was another terminology for it, it might be more acceptable to some people.
>
> SP They did try with the term pre-embryo.
>
> DW1 No I don't think pre-embryos. I think that you need to get rid of the 'embryo' all together
>
> [All agree]
>
> DW2 As [DM2] says, that's a real education, because I didn't know that and probably nobody else did – that it's before the actual formation of the embryo you're actually taking the cells. That's important because the first thing I picture is an embryo, you know, you see the beginning of a baby. That's the first thing I see. But that was very important and that should be emphasised. That particular aspect of it, the cell, the nucleus cell that's taken out.

And then later on in the discussion DW2 returns to this point:

> DW2 I think what cleared the way for me was that passage that [M2] read out. It's not actually formed yet because that was worrying me – the fact that it's the nucleus that's before it's feeling pain or anything. That's, you know, won me over to a certain extent.

I then I outline the 14-day limit for using human embryos for research purposes according to the arguments made in the Warnock Committee in the 1980s:

> DW2 That puts a completely different context on it all together. It's a personal thing I think.
>
> DM2 I think that you're probably quite right. I think that most people would probably baulk at the idea of a 24 week old foetus being used as I would. But I think that there has been a certain amount of disinformation spread by the popular press that that was the sort of thing that we were likely to face rather than a collection of a couple of hundred of cells which you can only see with the microscope. And maybe, as you were both suggesting, we need to find an alternative word for the embryo that isn't quite as evocative as the term 'embryo' is. Because I think the term 'embryo' has become irrevocably linked with the term foetus and of course, once people start to think, wow, I'm not going to play around with those.
> (Diabetes support group, 26/09/01)

As these exchanges show, for a number of the participants within the diabetes focus group, the meanings that they attached to embryo at the beginning of the meeting were not necessarily the ones that they left with. For instance, the embryo and the foetus were not seen as distinct entities but were placed on a developmental continuum where the teleology of the embryo is one that ends with a human child. For DW2, in particular, her view of embryos as potential children was informed by her experiences of three miscarriages, where she explains 'I was devastated every time I lost the baby'. However, when DM2 introduced the 'scientific' explanation of pre-14-day embryos, the group participants began to distinguish 'their' understanding of embryos from the technical meaning of 'early' embryos, and even called for a change in the terminology. To this extent, then, 'the embryo' (singular) was pluralised according to stages of development.

In comparing the view of people undergoing fertility treatment with the views of members of patient support groups there is an clear difference. For the former, one of the primary issues surrounding the use of embryos for SCR is whether embryos donated and used are 'viable'. For members of patient support groups, the main concern is to what extent an embryo has developed features that we associate with human beings. Within this group, but not for the fertility groups, the context in which the embryos are originally created are deleted, such as the experiences of the women who have undergone hyperovulation treatments to 'harvest' the eggs and the nexus of hopes and fears attached to embryos by 'couples' in fertility programmes. Moreover, the exchange of views within the diabetes support group illustrates how the 'scientised' embryo can be mobilised to actively expel other, more inclusive constructions of the

embryo from the frame.[5] Even when DW1 and DW2 introduced the experiences of women into the debate, this dimension was swiftly offset and the women within the group conceded that their experiential knowledge was less significant than scientific knowledge of embryos which prescribes a particular relationship between blastocysts and women.

The interview with the second Alzheimer's carer only briefly touched upon the use of embryos for SCR. The main reason for this was because AC2 was completely happy for embryos to be used for research purposes – although, like those in the diabetes support group, she acknowledged that her views wouldn't be shared by everybody. When I ask her how she feels about this topic she begins by telling me that both of her daughters have had miscarriages and that one of them has used assisted conception to conceive a child. One of her daughters' miscarriages took place when the foetus was five weeks old, and whilst her daughter was very upset, AC2W explains that it wasn't sufficiently 'human' enough for her to feel affected:

> AC2W It wasn't even a human shape, it was only just a tiny thing. But then I haven't experienced it, but to me this would have to be a little bit bigger and a little bit more human and not so much, I mean, these are little fishy shapes aren't they. What can you do with a mother like me? (Alzheimer's Carer 2, 03/10/01).

As she alludes to in this final sentence, she does not regard herself as a 'sensitive' mother. Indeed, she felt that she did not have the 'mothering instinct' but instead was more interested in what she called 'equal stimulation'. That is, her understanding of what constitutes a human being was something that one could interact with – or at least be large enough to 'see' the human form as we associate with a fully-developed human (i.e., not shaped like a fish). For AC2W, then, scientific and technological developments for visualising embryos have served to further distance embryos from more developed foetuses rather than ascribing subjectivity to them. That techniques that have rendered early embryos visible as fish-shaped objects, made it difficult for AC2W to oppose to their being used for SCR.

7.6 'Waste Not Want Not'

In the Huntington's Disease support group discussion, the use of embryos for SCR was also considered to be a contentious issue. Indeed, the second person to speak in the group directly addressed their concerns about using embryos:

---

[5] This idea of 'the frame', where some actors and practices are included in the frame and others are excluded, was introduced to me by Sarah Franklin in her presentation at the 'Gender, Genes and Generation' workshop, University of Lancaster, 26th & 27th June 2003.

HW2 I think that for some of us, the young ones, we felt that taking an embryo, taking bits and pieces, it's kind of horrific – although worse things no doubt have happened between the years. But you know, it's just the thought somehow (Huntington's Disease Support Group, 31/10/01).

After HW2 had opened up this topic for discussion other participants joined in and, in particular, the issue of where and how scientists obtain embryos was seen as their main area of interest. And as the following excerpt illustrates, the ethical and moral issues of using embryos was compared to using material from aborted foetuses:

HW1 What's the main source for the embryos?

SP Couples undergoing IVF, 'spare' embryos that are deemed to be non-viable for use for IVF.

HW1 So what would happen to these normally, would they just be destroyed?

SP They would maybe be frozen or left to perish.

HW1 That's why I don't see any problem, I've got children and I don't see any problem in using them.

[Talking over one another, agreeing with HW1]

HW2 I would not agree with a foetus being aborted simply to help somebody with Huntington's. But if a foetus is going to be destroyed anyway surely it's far better to do some good for somebody else. I mean I think this is the difference for somebody who's got children at risk [of Huntington's] and somebody who's not got anybody at risk and maybe could look at it a little more objectively. But I've got no problem with it.

HW You're much better helping somebody than wasting something.

HW2 I know but there are some people, Pro-Life groups would disagree with that. But I say, if they had children at risk they might change their minds.

HW Yes I would agree

[All agreeing]

HW4 It certainly puts a different slant on them.

HW5 But surely if they're being discarded anyway that's ... [interrupted]

HW That's better, that has to be the criteria as far as most reasonable people are concerned.

HW So what, I mean, why did Pro-Life people object to this

HW2 I think in principle they object to the use of embryos at all

SP The simple answer is because they believe that life begins at the point of fertilisation and that to use embryos, even if a few days old, is to destroy a life.

HW2 Well, we can't argue with that, but I say if a human being is going to be destroyed anyway, it's better to help somebody at least.

HW It's the same with aborted foetuses, provided that the foetus hasn't been aborted deliberately and it's been aborted naturally erm, you might as well make use of it. I mean it's like us giving blood for blood transfusions, you're saving somebody's life, you're helping somebody. So surely that's the thing, the significance, it's helping someone and it's no good to the person, you know, they've had a miscarriage which is upsetting for them but there's nothing they can do with it. So they might as well ... [interrupted]

HW Like we've said, if you've got somebody, you know, you've got someone in the family, your grandchildren and things like that with the possibility that they might develop Huntington's and all that then you know, I think it's worthwhile.

HW The only fear would be that you start saying, you know, I don't really want this child I'll abort it

HW But it's most unlikely, but I think from natural miscarriages (Huntington's Disease support group, 31/10/01).

In this lengthy exchange, the almost seamless slippage between embryos, children, foetuses and blood poses some interesting analytical questions for myself as researcher. Specifically, this prompts me to ask, according to what criteria are these 'entities' connected by the women engaged in this discussion? If taken in the broader context of what appears to have been the key matters at stake – under what circumstances embryos can be used for SCR – then I would argue that these different entities are enlisted into the jointly composed narrative by members of the group. Central to their understanding of embryo donation for SCR is whether the material in question is classified as waste. If embryos are not going to be used for reproductive purposes and foetuses have been terminated for reasons other than simply to be donated for research, then they are regarded as ethically acceptable sources of biological material for SCR.

On the issue of using aborted foetuses for SCR, participants in the Diabetes support group did not reach any consensus. As the discussion progressed one of the participants asked for some clarification on where adult stem cells can be taken from. I listed the examples of bone marrow and blood from adults and added that umbilical cord blood and cells taken from aborted foetuses are also potential sources of stem cells. To my surprise, DW2 did not regard the use of

aborted foetuses as problematic whereas DM1 raised concerns that women could be paid to become pregnant with the intention of terminating their pregnancies for research purposes. And whilst DM2, DW1 and DW2 regarded these fears as 'far-fetched', this did prompt a set of anxieties for M3:

> DM3 I think that there's an issue, especially when we've heard about there's so many brains and hearts and lungs in jars in hospitals and it's all come to light just recently. But I think that I don't know if I'd be one hundred percent comfortable if it was a child, erm, an aborted foetus and they were going to start playing about with it. I feel uncomfortable about that. Especially that I know it's not alive, I just feel uncomfortable that the pain I feel with interfering with something that I've created, I'd like it to rest you know. It's like a donor card, I've got two sons, if anything happened to my two sons, you know in terms of when somebody says well, you could use the eyes, the lungs and I do feel a wee bit uncomfortable about that. It's about not necessarily helping somebody but actually defacing, you know? I would say would you stitch everything back up again. It's just I feel uncomfortable, I feel like they would be destroyed again (Diabetes Support Group, 26/09/01).

As in the patient-led fertility support group, the recent organ retention controversy is invoked as a cultural resource for articulating a set of anxieties about scientific and medical research using human biological material. The perceived convergence of issues raised by the illicit retention of organs and the use of aborted foetuses in medical research, hinges on the extent to which the embryo/foetus/child can experience pain. Moreover, for M3, the ability to experience pain is intimately linked to whether an embryo is defined as a human life (albeit potential) or understood as a collection of cells. The conception and image of the foetus as a 'life' that can feel pain, makes it difficult for M3 to consider foetuses as ethically acceptable sources of biological material for SCR. And if we turn this around, the use of embryos for SCR is afforded some legitimacy on the grounds that they cannot feel pain. It is through this connection that we can reflect upon the ongoing significance of the scientific model of pre-14-day embryos, as established in the 1980s, for generating legitimacy for all forms of embryo research.

7.7 Conclusions

In this chapter I have explored the views of participants from the fertility and patient support groups in order to highlight the multiple and flexible meanings associated with embryos. As such, I have pointed to a range of factors that are relevant to the (re)construction of embryos vis-à-vis SCR. For instance, visual and linguistic representations of blastocysts that have come to constitute the dominant public discourse on embryos in the UK, also had significant currency within both the fertility and patient groups who participated in this research. This is exemplified

within the Diabetes support group, where the reconstruction of embryos takes place during the group discussion. As already shown, the intervention of DM2 with Wilmut's technical description of eSCR can be seen to have altered the perceptions of other participants. Similarly, within both of the fertility support groups, their understanding of embryos according to 'viability' discourses was a key component in shaping their perceptions of research using human embryos.

However, what was regarded as 'spare' differed across individuals and groups and was contingent upon their embodied and lived experiences. Within the fertility groups, for instance, participants who were still undergoing fertility treatment only regarded non-viable embryos as 'spare' – and therefore *potentially* available for SCR (although this was not unanimous). Only one participant, whose wife had already had a child and was probably not going to continue with treatment, suggested that he [sic] might donate their spare viable embryos for research. At the point when the focus group took place it did appear, however, that he would only donate embryos for research that remained within the field of reproductive medicine rather than SCR. This nuanced account of what 'spare' means was not present within the patient groups. Instead, 'spare' was understood as embryos that would otherwise be allowed to perish and the issue of viability was not explored. But given that nobody from the patient groups had undergone fertility treatment (to my knowledge) and I did not raise the issue during the discussion, then it is perhaps not surprising that such embodied accounts of embryos did not emerge as a key concern.

Within the patient support groups, views of eSCR are linked to their embodied experiences of illness, or of family members. As shown in section 7.5 and 7.6, some members of the Huntington's and Diabetes support groups appealed to their experiences of health and illness when considering the use of embryos for medical research. Whilst their shared identities as members of a particular patient group was privileged, other aspects of their identities emerged during the discussion. For instance, participants drew upon their knowledge as parents and grandparents (e.g., in the Huntington's support group) or as women who had experienced miscarriages (e.g., DW2) and childlessness (DW1). It is often in the switching between these identities that the contradictions and ambivalence towards eSCR are revealed – as it become difficult to resolve, for example, the tensions between embodied understandings of embryos (as women or childless) and experiences of incurable conditions (such as Diabetes).

A further interesting aspect of the discussions is the way in which eSCR both re-opened the embryo debates and in some instances was seen to further unsettle meanings around the range

of possibilities associated with embryos. The teleological end point of embryos (and foetuses) as human babies had already been disrupted by previous embryo debates. In this sense, ongoing developments in the field of reproductive technologies – from abortion to pre-implantation genetic diagnosis – have already produced new teleologies that overlap and blur into one another. Accordingly, whilst embryos can become children, the range of possibilities also include being frozen and stored, being left to perish, implanted into the 'mother' who then miscarries, used for implantation into a woman other than the source of the oocyte, or used by clinicians to practice fertilisation techniques. Developments in SCR has added a further possibility for embryos, where the negotiation over the social, moral and ethical implications of this area of research involves the reconstitution of embryos. The acceptability of these various teleologies, however, is not evenly distributed but instead engenders a great deal of ambivalence and, sometimes, anxiety.

The dominant rhetoric of embryos in the parliamentary debates as eventually enshrined in the amendment to the 1990 HFE Act, takes for granted a) the willingness of 'couples' to donate their embryos for SCR and b) that people with conditions such as Diabetes are 'demanding' the development of eSCR and take a utilitarian view of embryos – as a means to an end. However, as I have tried to show in this chapter, the meanings attached to embryos by individuals is not determined simply by their 'health' status as 'infertile' or having 'Diabetes'. The complexity of our identities – as, for instance, women, parents, or patients – are partial and fragmented where we cannot 'read-off' a person's understanding of embryos and embryo research from any one aspect. For instance, to briefly consider F2W1 in the Sister-led fertility support group, her perception of embryos and their uses in SCR is shaped by a number of factors. If we trace her contributions to the discussion we can identify some key points that illustrate this argument, including having a family member with Huntington's Disease compelling her to 'want to help' (see 6.5), and her experiences of undergoing fertility treatment where viable embryos are regarded as 'precious' and so should not be donated for SCR compared to non-viable which were seen as accepted sources of embryos for SCR. Although this is only one individual case, exemplifies the conflicting and contradictory factors shaping people's views of developments in SCR.

What this chapter has shown is how embryos are subject to a range of constructions and meanings by different actors. From this, my analysis illustrates that we need to develop a more sophisticated understanding of the meanings attached to embryos, how these views are formed and how they relate to people's own particular embodied experiences in complex and contradictory ways. As Edwards has argued, we need to develop more sophisticated ways of

hearing publics' views (2002), and to this extent, in-depth interviews and focus groups are shown to be effective methodological approaches for achieving such aims.

A final point relates to the provisional nature of people's accounts in both this and the previous chapter. Given that many of the people who participated in this research only began to consider their views on SCR and cloning-related developments during the focus groups, there are strong reasons for thinking that their views may have changed since that meeting. As the follow-up correspondence from F1W2 indicates, the views expressed during the focus groups and interviews were often spontaneous thoughts, triggered by others within the group. Follow-up focus groups or interviews may reveal differences in participants' accounts, especially as SCR and cloning become entrenched and gain public acceptability over time.

CHAPTER VIII

Destabilising Nature? Renegotiating Cultural Categories in the SCR and Cloning Debates

> If human beings once knew what 'nature' was, they do so no longer. What is 'natural' is now so thoroughly entangled with what is 'social' that there can be nothing taken for granted about it any more. In common with many aspects of life governed by tradition, 'nature' becomes transformed into areas of action where human beings have to make practical and ethical decisions (Beck, Giddens and Lash, 1994: vii).

8.1 Introduction

This chapter continues to develop some of the key analytical points raised in previous chapters, such as public ambivalence about science and technology, the role of embodied experiences in shaping ones views of SCR and cloning, and the mobilisation and negotiation of sociocultural categories in accounts of this area of research. At the same time, this chapter makes a distinct break from previous chapters. As indicated in the opening quote from Beck *et al.*, I will be concerned with both the mobilisation of 'nature' as a category for understanding SCR and cloning and the processes by which 'nature' is negotiated, transformed and (re)constructed.

This chapter has emerged for three reasons. Firstly, I had an existing interest in constructions of 'nature' and the significance of binary categories for ordering the social and natural worlds which developed during my Masters degree in cultural studies. During my postgraduate degree I began to become interested in feminist poststructuralist theory, such as Judith Butler's work on gender and the sexed body (1990, 1993) and Donna Haraway's early work on the cyborg (1991, 1997b). In the event, these theorists do not figure highly in this chapter (indeed, Haraway is not discussed at all), but they have played an important role in forming my underlying interest in constructions of 'nature'. Secondly, my pre-existing interest led to me sensitise my analysing of the interview transcripts to how 'nature' is mobilised, (re)constructed and transformed within the SCR and cloning debates. Thirdly, background reading of cultural commentaries and media accounts on SCR and cloning indicated that this area of research (like many others in the new genetics, such as xenotransplantation) is a limit case. That is, current and potential practices in this area exist at the edge of 'received wisdom' of human bodies, identity and the realms of possibility. The 'cloning' dimension, in particular, has been presented as challenging 'nature' or the 'natural order' of life itself, challenging meanings around what it is to be human and

intervenes in processes that are regarded as fundamental to the human condition – reproduction. Furthermore, narratives of cloning have a long history in literature and film, appearing as limit cases that signify 'ultimate' control of human bodies and biology.

What this chapter does, then, is to focus upon the dynamics involved in negotiating and classifying SCR and cloning as 'natural' or otherwise. I begin the chapter (in Sections 8.2.1 and 8.2.2) with a discussion of relevant theories that have informed my understanding of 'nature'. Then, I go on to show how distinctions between binary opposites, such as nature/culture, are central for the processes of meaning-making and yet these are managed in flexible ways by those who participated in focus groups and interviews. I also highlight ambivalence and contradictions within people's accounts in order to illustrate that boundaries between categories are blurred. Flowing from this, I illustrate how in unsettling cultural categories around 'nature', the SCR and cloning-related developments reveal the social constructedness of 'nature' to me, as the analyst, as well as to those that participated in the discussions. This chapter is ordered around four themes – kinship, human uniqueness, reproduction and the human life course – I draw primarily upon the accounts of those in the patient support groups in order to explore the sociocultural processes involved in constituting nature.[1] To a lesser extent I draw upon the accounts of core-eSCR-scientists and other relevant material available in the public domain (e.g., the media). I would have liked to have included a more detailed analysis of media accounts but was constrained by time and space.

The chapter concludes with a brief summary of the main points raised, drawing together some of the overarching themes pertinent to my analysis. I then return to the theoretical and conceptual tools introduced in sections 8.2.1 and 8.2.2. Whilst an effective melding of theory and empirical data requires further analytical work, my conclusion suggests how my analysis of sociocultural categories in the SCR and cloning debates may proceed. Specifically, I argue that SCR and cloning debates are potential openings for social scientists to explore, deconstruct and reveal the social constructedness of categories of 'nature'. If cultural categories are unsettled by these developments, social scientists can make interventions into the cultural processes involved in the entrenchment of this area of research, revealing new ways for ordering and thinking about the social and natural worlds.

[1] As in previous chapters, whilst I have isolated excerpts and placed them in particular sections, many of the accounts presented contain themes that correspond to other sections. Therefore, when following my analytical discussion it is important to note this artificial separation of issues.

8.2.1 'There's Nothing Natural About Nature'

Before entering into a discussion based upon my empirical data, I will first introduce some of the theoretical approaches and concepts that underpin my analysis of participants' accounts. Here, I point to a range of related approaches in order to explicate a broader understanding of how I understand 'nature' and its significance for analysing the SCR and cloning debates.

The importance of binary categories for ordering and understanding the 'social' and 'natural' worlds has been documented by a number of writers spanning across social science disciplines (see, for example, Douglas, 1966, 1970, 1975; Franklin *et al.*, 2000; MacCormack, 1980; Macnaghten and Urry, 1998, 2000; Michael, 2000; Soper, 1995; Turney, 1998).[2] 'Facts' about 'nature' – as opposed to culture, science, technology and so on – along with distinctions between these binary categories, continue to be central to thought, knowledge and practice. In interrogating categories of 'nature' in its various contexts, many writers have revealed their sociocultural constructedness, where what is deemed to be 'natural' or 'unnatural' is achieved through processes of negotiation and contestation. That is, categories exist in their context of usage as a classificatory system that serves as a powerful rhetorical tool through which we can include or exclude particular behaviours, practices, objects and even people. Therefore, categories such as 'nature' and 'culture' are not value free, unmediated systems of arbitrary signs, but are generated by sociocultural practices in particular contexts: there is nothing natural about 'nature' (see MacCormack, 1980, Macnaughten and Urry, 1998, 2000).

In *Frankenstein's Footsteps* (1998), Turney illustrates how biological research and medical developments involving the human body have always evoked deep-rooted, feelings of hope and fear. He argues that 'biology offers the prospect of ultimate control over or transformation of the living realm' which means that, for publics and scientists alike, 'biology is indeed 'no ordinary science'' (Turney, 1998: 37). In keeping with the thesis as a whole, in this chapter I will show how SCR and cloning-related developments provoke complex responses which, like Mary Shelley's *Frankenstein*, expresses the desire and fear of 'technology's ability to break down old boundaries, and dissolve taken-for-granted categories' (Turney, 1998: 2). Cloning practices, whether for 'therapeutic' of 'reproductive' purposes, generates anxieties about the certainty of boundaries such as between self/other, normal/abnormal, human/non-human.

[2] Analyses of the production of binary opposites as central to the formation of human society date back to Structuralist theories, such as the linguist, de Saussure, and anthropologist, Lévi-Strauss. Furthermore, anthropological evidence demonstrates binary classificatory systems are not peculiar to Western societies (see Douglas, 1966; 1970; 1975; MacCormack and Strathern, 1980).

To argue that categories for ordering our world, such as 'nature' and 'culture', are inextricably linked with the sociocultural context in which they exist is a well-established and well-worn position in sociology today. Historical and anthropological research have clearly demonstrated how what is understood as 'natural', and the ensuing practices surrounding these beliefs, vary significantly depending upon the sociocultural context. What is clear from the research of people such as Lévi-Strauss and Douglas, however, is that whilst categories of nature are socially constructed this is not to say that they can be easily re-constructed or even 'undone'. Symbolic systems relating to the nature-culture binary have been shown to be durable and to a great extent immutable across cultures and history. Whilst the content of the binary varies, the existence of dualistic categories remains relatively constant as a powerful trope. Therein lies the paradox of such categories, that is, both their immutability *and* their malleability. In the following chapter I aim to elaborate on this paradox, through exploring the ways in which idioms of nature, as a classificatory process (Franklin *et al.*, 2000: 1), are mobilised in flexible and contradictory ways.

Whilst such classificatory systems are ordered according to binary opposites, these are constructed relationally in a process of co-production. In arguing for such a conception of binary categories I am suggesting two things. Firstly, that reflections upon, for instance, the nature-culture binary, involves reflection of other categories (see Douglas, 1966: 5). This is not to say that nature = health = normal and culture = illness = abnormal, for example, but simply to say that there are borrowings between different categorical domains (see Franklin *et al.*, 2000: 8-11). Secondly, the relationship between binary opposites is often complex and contradictory, illustrating how '*nature and culture have become increasingly isomorphic while remaining distinct*' (Franklin *et al.*, 2000: 9, original emphasis). For instance, IVF practices intervene in, or assist, 'natural' processes of human reproduction and biology. In such cases, it becomes difficult to disentangle categories of 'nature' from those of 'science', 'technology' or 'culture' (I will develop this point further in later sections).

In considering people's views of SCR and cloning-related developments, what becomes clear is the significance of binary opposites for thinking, understanding and communicating our views. As I will show in this chapter, the mobilisation of binary opposites is not simply an uncritical reproduction of dichotomies, but involves an interrogation and reworking of dominant categories. In investigating the views of, primarily, members of patient groups and also scientists' and media accounts, this chapter will demonstrate how, 'habits of thought ... that reproduce themselves in our communications *never reproduce themselves exactly*' (Strathern, 1992a: 6, original emphasis). Therefore, public debates on SCR and cloning are sites where we can observe the

(re)production of binaries and reveal the social constructedness of classificatory systems in action.

A further point that I would like to emphasise is that 'nature' is constituted in multiple ways through dynamic practices that are embedded in both the sociocultural context and ones embodied and lived experiences. This process of negotiation and contestation is captured in Franklin et al's. (2002), conceptualisation of 'nature'. They argue that categories of 'nature' are undergoing processes of denaturalisation and renaturalisation, where 'nature' is contemporaneously challenged, renegotiated and re-asserted. Developments in areas such as the new genetics, they argue, do not undermine categories of 'nature', but instead, understandings and meanings of 'nature' are redefined or shifted. Again, this points to the malleability and durability of 'nature'

8.2.2 'Cloning' As Cultural Taboo?

Human cloning, like many other technoscientific practices that alter the body, has acquired the status of taboo and is now subject to primary legislation in the UK.[3] The power of human cloning as a taboo has fuelled the imaginations of science fiction writers for over half a century, dating back to the publication of Aldous Huxley's *Brave New World* in 1933. Since then, the technological future of cloning has been explored in varying depths in literature, film. Also, even though reproductive cloning did not become a technological possibility until the production of Dolly the sheep in 1997, discussions on the subject had already figured in the parliamentary debates on embryo research during the 1980's. This illustrates that the status of human reproductive cloning as cultural taboo, predates its technological feasibility.

The production and maintenance of cultural taboos, whilst often accompanied by a legislative ban, is a generative process. In keeping with a Foucauldian notion of regulation, discursive techniques which aim to control and prohibit ideas and practices result in the proliferation of those same ideas and practices (see Foucault, 1979: 15-49). To claim that cloning is a taboo is not to claim that human cloning is unthinkable and unspeakable. On the contrary, cloning has served as a fruitful trope in science fiction to explore the boundaries around the self, identity, humanness and nature (see Van Dijk, 1999). Indeed, science fiction has been one of the primary vehicles for exploring the implications of human reproductive cloning and has engendered a

[3] See http://www.hmso.gov.uk/acts/acts2001/20010023.htm for details of the Human Reproductive Cloning Act 2001.

range of discursive repertoires for imagining the future (see for example Mulkay, 1997, Rose, 1994). Today, with the potential of a technological realisation of cloning-related practices, those very same boundaries are being explored as part of the public debates on human cloning.

The maintenance of human cloning as a cultural taboo has a twofold function. Firstly, it rules out these discourses and practices relating to SCR and cloning developments which threaten to disrupt the social order. That is, disruptions to ideas such as those around human uniqueness, identity and selfhood. Such processes are evident in the rhetorical separation of 'therapeutic' from 'reproductive' cloning. Secondly, taboos function as regulatory mechanisms whereby boundaries within classificatory systems are (re)asserted: to separate the 'natural' from the 'unnatural', purity from defilement. As Stacey has argued 'cultural taboos ... are reproduced in order to secure distinctions' (1997: 75). That cloning is unsettling, or what John Clark called 'an intrinsic taboo' (personal interview, 28/11/01), indicates the presence of abjection. Abjection, as defined by Kristeva, 'is not lack of cleanliness or health ... but what disturbs identity, system, order. What does not respect borders, positions, rules. The in-between, the ambiguous, the composite' (1982: 4). The abject is contradictory, it is met with both fear and desire; it is that which is jettisoned from dominant classificatory systems and yet requires purification. Indeed, abjection, the act of jettisoning objects, ideas or groups, functions as a means of purification – to create binaries or distinctions between the acceptable and the unacceptable.

Butler's account of abjection describes how abjection is to 'cast off, away, or out and, hence, presupposes and produces a domain of agency from which it is differentiated' (1993: 243, n2). She then goes on to say that, according to Lacan's theory, the abject 'may not reenter the field of the social without threatening ... the dissolution of the subject itself' (Butler, 1993: 243, n 2). Here, the dissolution of the self would occur through dominant classificatory systems being challenged by the abject. That which is constructed as outside, other, or beyond the limits of acceptability is constituted as such not to protect social life. Butler argues that abjection (the expulsion of something as 'other') is part of the matrix of binaries – nature/culture, normal/abnormal – which are mutually constitutive categories. The abject, however, reveals the *instability* of this matrix because it is unplaceable and, to some extent, beyond the limits of classification or located within a 'third space'. Therefore, the abject by its mere existence poses a threat to the classificatory system through which identities, and by extension, the subject is constituted.

Like Douglas' theories of symbolic systems of pollution and disorder (see 1966, 1970), Kristeva's abjection is a useful concept for exploring ideas and objects that exist at the

boundaries and threaten to disrupt social order. Both Douglas' purification and Kristeva's abjection point to the social constructedness of classificatory systems. As a post-structuralist, Kristeva, however, departs from Douglas (who is a structuralist) in her implicit understanding of binary categories. Whereas Douglas' work explicitly argues that the social and natural worlds *are* ordered according to binary opposites, Kristeva's abjection allows us to theorise the borders: the in-between. Theorising abject zones is useful for examining the (re)production of classificatory systems as a dynamic and relational process. According to this perspective, new developments such as SCR and cloning do not simply become incorporated into the existing classificatory system but are productive and generative of categories as well as indicating a moment of potential change.

Although abjection has often been utilised to conceptualise bodily fluids in relation to bodily boundaries (see, for example, Longhurst, 2001),[4] I would argue that the concept also lends itself to an understanding of public responses to SCR and cloning developments. The constitution of cloning as abject is demonstrated in this chapter. Using a combination of excerpts from focus groups and interviews, plus extracts from various public sites within which the cloning debates are taking place, human cloning is shown to be a site at the boundary of what constitutes 'nature'. It is both, either and neither natural or unnatural, acceptable and unacceptable; it is expelled, disavowed and yet is at the same time entertained (e.g., as an example of scientific progress). Such contradictory responses to the developments of cloning which posit cloning as abject, confirms how classificatory systems are cultural constructions that are subject to cultural interpretations and therefore to negotiation. Furthermore, whilst people's thinking of human cloning is structured by such classificatory systems, it is not determined by them. What is regarded as natural or unnatural is subject to the particular and complex, sociocultural and lived experiences that a person or group have encountered. What this chapter demonstrates is that individual responses to technoscientific developments such as SCR and cloning cannot be predicted according to single causal factors, such as direct experience of Alzheimer's or infertility, but are produced according to complex, and often unique, combinations of lived and embodied experiences.

[4] For instance, for theorising the categorisation of menstrual blood, sweat or urine as waste or dirt.

8.3 Reproductive Cloning and Kin Relations

In the fields of anthropology, sociology and cultural studies, the implications of assisted conception practices for kinship relations have been well documented (see, for example, Franklin, 1993; Graham, 2002: 111-116; Strathern, 1992a,). Since their inception, developments in new reproductive technologies (NRTs) have unsettled taken-for granted boundaries and cultural categories. In particular, interventions into reproductive processes have been shown to reconstitute representations and understandings of what constitutes 'natural' or 'unnatural' kinship relations. For example, Franklin has argued that the advent of gestational surrogacy[5] has created a 'new form of 'blood tie' ', where the relationship between the child and surrogate mother 'has no categorical foundation within the 'natural order' upon which kinship classifications and definitions are based' (1993: 551). Similarly, the birth of the first IVF baby, Louise Brown, in 1978, resulted in the negotiation of categories of nature, where 'natural facts' about reproductive processes can no longer be regarded as authoritative accounts.

There are two key points to take from such examples that are pertinent to the arguments made in this chapter. Firstly, assisted reproductive practices such as IVF and surrogacy, have not replaced 'natural' forms of human reproduction, instead 'assisted' and 'natural' procreative practice co-exist alongside one another.[6] To this extent, both 'traditional and detraditionalised versions of nature co-exist' (Franklin *et al.*, 2000: 13). Secondly, after twenty years of development, these reproductive technologies have undergone processes of entrenchment and become a naturalised technique for assisting the production of a family (see chapter 3).[7] This illustrates that boundaries between nature/culture are not fixed but are permeable and that practices that were once deemed to challenge the natural order of things, can be reconstituted to reinforce 'nature'.[8]

---

[5] In this context, Franklin is referring to surrogate mothers who have no genetic link to the child which they gestate, rather than surrogacy using the eggs of the surrogate mother.

[6] Although we should note that some interventions into the female reproductive body, such as caesarean sections and amniocentesis, have become routinised and are widely practiced.

[7] Notwithstanding ongoing opposition from those adopting pro-life positions. In addition to this, a number of feminists continue to offer critical interventions into the exclusion of women's voices and experiences along with the intense medicalisation and surveillance of women's bodies involved in fertility treatments and related social processes (see, for example, Ettorre, 2002).

[8] Franklin has shown how assisted reproduction has been subject to various and competing constructions, for instance, as either challenging or reinforcing 'natural' facts' around motherhood and kinship (1993).

Twenty years on from the birth of Louise Brown, boundaries around kinship and relatedness vis-à-vis nature have been unsettled by developments in reproductive cloning. With existing NRTs, including gamete donation and surrogacy, reproduction is achieved through the fusion of male and female gametes and, therefore, each person produced through NRTs has a biological mother and father. This is not to suggest that other NRTs do not lead to different kinds of kinship configurations; as Charis M. Cussins has shown, egg donation 'disrupts the coherence of the natural ground for bilateral linear descent' and reveals other ways of "doing" kinship (1998b: 42-43). The theoretical possibility of reproductive cloning, however, departs from previous NRTs in the sense that any births arising from this technique would only have one biological parent.

In the Sister-led fertility support group, participants talked about their concerns that SCR would lead to reproductive cloning. I then asked why they believed there is a difference between IVF and reproductive cloning since both can be seen as assisted conception techniques:

> F2W2 Because with IVF you're reproducing yourself and your husband but with cloning you're producing one or the other. It's not both.
>
> SP Is it important for reproduction to be a mixing of gametes rather than just one?
>
> [General agreement within group]
> (Sister-led Fertility Support Group, 27/06/01)

A key issue for F2W2 was the biological lineage of children from two parents – one male one female. To have a child that was produced from one person was regarded as unsettling. Significant to this distinction between IVF and reproductive cloning is the process of naturalising IVF through aligning it with 'natural' reproductive processes of gamete fusion. Whilst cloning could achieve the same ends as other NRTs (the birth of child), participants in the Sister-led fertility support group were unwilling to ascribe legitimacy to reproductive cloning as a new reproductive technology.

Conversely, in the cardiac support group, reproductive cloning was argued as being similar to surrogacy in terms of disrupting kinship relations:

> CM1 Well what is a surrogate child? It mightn't have anything to do with the mother at all. It mightn't have anything to do with the father.
>
> CM4 A surrogate child is naturally produced.

CM1 It's not, that's the trouble, it's not

SP Do you think it's different because with surrogacy the child is made from an egg and a sperm, even if another woman gestates it?

CM1 And brought up by two other completely different folk, they're not even who the originals were.

CW2 Imagine the world.

CM1 And what does that amount to? A lot of money changing hands.

CW1 You're doing a comparison there.

CW2 I mean, can you imagine the world in a hundred years. Brothers and sisters don't know who, or what ...

[People talking over one another]

CW2 You could be married to your brother and not know about it, or your sister or ... [interrupted]

CM4 That already happens. That has happened.

CM1 A lot has happened (Cardiac Support Group, 18/07/01).

The combination of reproductive cloning, surrogacy and incest provides a window on participants' understanding of kinship. In connecting other examples where kinship relations are unsettled, we can see the processes of meaning-making involved as people negotiate kinship. Furthermore, the contribution made by CM1 suggests that assisted reproduction techniques, such as reproductive cloning and surrogacy, are not amenable to categorisation. Such practices seem to produce a degree of reflexivity, with participants reflecting upon the social constructedness of kinship relations.

The relationship between a potential cloned child and its parents/sibling was also identified as a central concern.[9] As the following set of excerpts illustrate, participants in the patient groups argued that clones would feel like replacement people, or copies of existing family members rather than unique members of the family:

F2W3 I personally think that it would put an awful lot of pressure on that poor child. You know, what's the child's life going to be life, you know, it's a replacement of the original basically. In this day and age, so much pressure is put on a child as it is. What kind of pressure is that child going to be under, knowing

[9] A cloned child would be the genetic twin of the person cloned. This problematises our understanding of the genetic relationship between children and parents, and between siblings.

> that yes, it was wanted desperately, so much so that somebody cloned them? But people are going to say it's a replacement (Sister-led Fertility Support Group, 27/06/01).
>
> AC1M It would be an individual but how would they feel about being an exact physical copy of someone else? They might not feel that they're an individual. Goodness knows what psychological problems it would bring and also how other people surrounding would look. You know, "ha ha, he's a clone" at school, you know, goodness knows what. So I would think that the individual would face some very, very serious problems. I don't, I notice that I just used the word "individual", erm, I didn't mean it in that sense. But I don't think that the personality could be the same as the father, say (Alzheimer's Carer 1, 21/09/01).
>
> HW5 The thing that worries me, I'm concerned for these poor children that a) are lumbered with these people who aren't concerned for the welfare of this child, and b) that they are lumbered with those parents. ... I think that the parents would try to pressurise them into being something that they are (Huntington's Disease Support Group, 31/10/01).

In quite different ways, these excerpts exemplify how reproductive cloning engenders shifts in the nature and meaning of relationships amongst kin. Reproductive cloning brings about new connections between children and their parents, which, for the three people quoted above, generates anxieties. In a context where definitions of parenthood are already problematised – e.g. between social and biological parents (see Strathern, 1992a) and procreation is subject to discourses of choice and responsibility (see Ettorre, 2000, 2002) – reproductive cloning marks the latest development to potentially redefine relations between kin.

A further dimension to the above accounts relates to people's understanding of the role of genes in the formation of identity and personhood. In raising the issue of parents' expectations of cloned children, people are implicitly binding cloned children to their genes, or at least as played out in kinship relations. If we pick this argument apart, the risk identified by participants is a complex and contradictory one which can be expressed as follows: the environmental conditions (e.g., the family context and expectations of 'parents') would place clones in a context where they are constrained by their genes. This is an interesting argument, because is suggests that genetic determinism is environmental in its origins – genetic determinism via social determinism.

A similar point was also made by Ian Wilmut, who separated therapeutic from reproductive uses of the cloning technique on the basis of child welfare issues:

> Wilmut: I don't like the idea of human reproductive cloning because I don't think that it would be much fun to be a clone. Because I think that the sort of similarities between the original and the copy would be very great and the

> expectations between them would be different and so the whole relationship would be different. So I don't see it as being catastrophic or kind of life-threatening as it were, but I see it as an issue of child welfare (Roslin Institute, 13/09/01).

He then goes on to ask:

> Wilmut: What would it be like to be a genetically identical copy of your parent? (Roslin Institute, 13/09/01)

Here, genetics-environment debate is held in a fine balance and clones are seen to embody the inherent tensions of determinist positions. Such views have been expressed across a number of contexts, including media debates. For instance, in his contributions to a televised debate on cloning, Grahame Bulfield of the Roslin Institute argued:

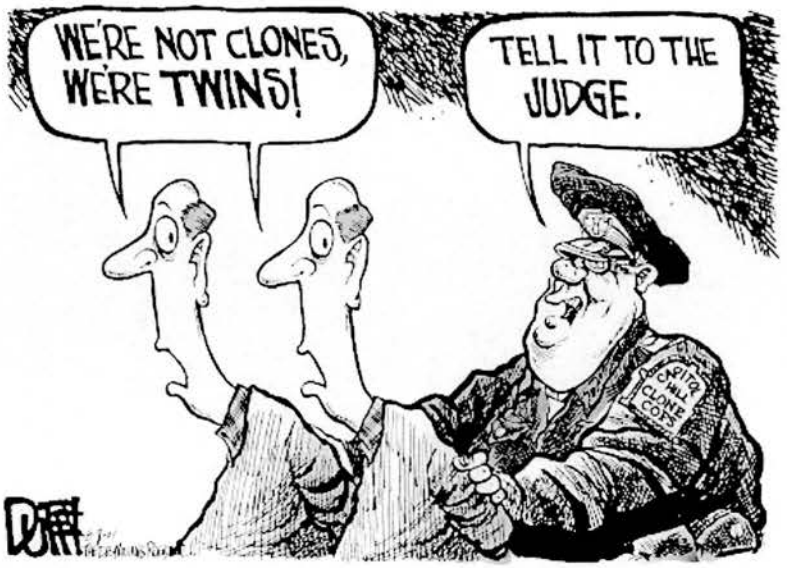
> As a geneticist I always think the environment is far more important than genetics is. I would say the environmental influences are pretty dramatic. I think it is a very interesting point that the clone would almost see their future in their "parent". That might be a difficult thing to live with (Grahame Bulfield, in Cloning Debate from "Every Man". http://www.world-of-dawkins.com/cloning_debate.htm [20/06/01]).

And in an article from *The Guardian* newspaper, the novelist and cultural commentator Eva Hoffman stated:

> From the child's perspective, what would it be like for a daughter to realise that she has no biological father at all; that her grandfather is in effect her father; and that her mother is her genetic twin? ... Twins are not made to order they come to their parents as a surprise, and they are firmly situated within their own generational lifespan ... Of course, a cloned child *might* go on to develop its own consciousness and autonomous selfhood; but the normal difficulties of separation and individuation would be hugely magnified (Eva Hoffman, *The Guardian*, Aug 29 2001, own emphasis).

Reproductive cloning, it seems, combines a number of pre-existing problematic aspects of child-parent relations as well as generating novel ones. For instance, cultural repertoires around child welfare vis-à-vis the implications of parental expectations are not novel issues. Indeed, since the advent of assisted reproduction practices such as genetic testing and sex selection, it is difficult to maintain the argument that children come as a complete surprise. So again, this returns us to debates about the role of genes in shaping our identities – who we are and who we *can* become.

8.4 Human Uniqueness: Genes and Twins



Source: Brian Duffy, http://cagle.slate.msn.com/news/cloning/5.asp [26/02/03].

In the focus group and interview discussions, human uniqueness was mobilised as a discursive repertoire when exploring their views of reproductive cloning. As indicated in the previous section, people's accounts of clones and cloning implicitly revolve around the genes-environment debate. And, for many, the spectre of reproductive cloning raises the question of what constitutes a unique human being? Following on from the above discussion, I will now turn to the issue of human uniqueness and individuality, exploring how people negotiate meanings around human identity. In particular, I will highlight how twins has been a recurrent theme in the cloning debates and in the accounts of people in focus groups.

The notion that each individual is a unique person is a salient one in Western cultures. Whether it is an argument based upon genetic determinism, social determinism or a mixture of the two, the construction of the self in contemporary society is based upon ideas of individuality and uniqueness. This is evidenced in many sociocultural spheres ranging from consumer culture where advertising strategies are employed which interpellate the subject as unique, to the new genetics which individualises the subject according to their genetic make-up. At the same time, however, genetic knowledge (e.g., the Human Genome Project) identifies similarities and patterns between human populations, as well as between humans and non-humans. To this extent, then, there is a play between unity and uniqueness in contemporary culture, where we are interpellated in terms of sameness and difference.

Twins have served as a potent site for investigating both biological and cultural aspects of human uniqueness across a variety of cultures (see, for example, Douglas 1975). Since Galton's initial study of twins, published in 1875, the twin study method has been used to explore the genes-environment debates of human behaviour, psychological traits, language and intelligence (Garfield and Holton, 1984). Alongside natural science analyses, research on twins has informed discussions around human uniqueness, individuality and identity within the cultural sphere, where similar questions have been explored. In film, literature, art and folk tales, twins have been utilised at a symbolic level to explore questions of humanness, suggesting that symbolically, twins inhabit a contradictory space. They are both the same and other to the degree that they disturb constructions of 'reality' and human uniqueness (see Sadri, 1994).

Mary Douglas has shown how in the Lele tribe, twins and their parents are ascribed a special status, where 'twin children are spoken of as spirits and their parents as Twin Diviners' (1975: 35). Locating twins and their parents in the spiritual realm of the symbolic order Douglas show how, in the Lele, twins are seen as transgressing important socially constructed boundaries. Similarly, we can observe how in contemporary Western societies, twins are also ascribed a special status which has been taken up by many in the human cloning debates (see Sadri, 1994). In imagining a future with human cloning, it is perhaps unsurprising that people have turned to 'natural clones' as a cultural resource and subsequently, social boundaries are explored, negotiated and, often, redrawn. In this section I explore how cultural representations of twins have informed the cloning debates.

There are numerous myths and urban legends surrounding twins and cloning. A particularly evocative myth is that of the "doppelganger". A doppelganger, meaning "double walker", is often reported as one's double that walks alongside oneself but cannot be seen (see, the *Merriam-Webster Dictionary*).

Source: Unknown.

Significantly, the myth states that to come across one's own doppelganger indicates bad luck or even imminent death. In relation to the theme of "double walker", whilst not directly referring to the doppelganger myth, some of the views articulated in the focus groups confirm the concerns which underpin the myth. For instance, in the cardiac support group, participants talked about whether a clone would be a unique individual or not:

> CM1 I think that it would be an individual, irrespective of whether it was identical to somebody else.
>
> CW1 It depends. If it knew it was a clone it might feel as though it's in the shadow of somebody.
>
> CM1 It might want to get rid of it (laughs). There's a new one now, get rid of that one.
>
> CW1 Depends on how much on how much it would take of the personality of that it was cloned from. How much has got ... [interrupted]
>
> CM1 Transferred.
>
> CW1 ... [continuing] transferred of that. So then you could feel as though you're, obviously, in the shadow of somebody. Felt as though you're always having to do as good or you know, expected to do better.
>
> CM1 That's what one of the basis of one of the future legislation as to whether or not a clone could have its other half still alive or whether it is an individual in its own right.
>
> SP So that you could only clone a person once the person was dead?
>
> CM1 Or possibly dying ... Well, erm, if it was that the person to be cloned was no longer alive then the clone would just be an individuals original. Then they wouldn't have any, it would just have to grow in its own way (Cardiac Support Group, 18/07/01).

Here, there are references to living in somebody's shadow and to have a person co-existing with their clone was perceived as troubling the boundary between self and other. Again, the genes-environment debate implicitly figures in the above accounts, with CW1 unsure whether a clones would directly inherit personality traits from the person cloned.

Participants in the Sister-led infertility support group also discussed their anxieties about having both 'originals' and clones living simultaneously. This issue was framed around the problem of identifying criminals if either the clone or cloned committed a crime. Subsequently, participants suggested that one solution would be to regulate when a person can be cloned:

CW2 Maybe they should do it after the person has died. Then there'd only be one with that DNA

CW4 (Laughing) Then people would be thinking, "you'd better die so I can clone you" (Sister-led Fertility Support Group, 27/06/01).

In tying reproductive cloning in with their knowledge of genetic fingerprinting and forensics, participants identify cloning as not only an ontological problem, but a practical one.

Films such as *The 6th Day* illustrate how the ideas underpinning the doppelganger myth serve as powerful cultural resources for imagining future scenarios of reproductive cloning. In *The 6th Day*, death can be 'undone' through secretly cloning people soon after their death. The memories of the 'original' are then implanted into the clone who would continue with their lives without either themselves or their friends and relatives knowing that they are a clone. The plot is based around Arnold Schwarzenegger's character who is mistakenly cloned whilst still alive. What ensues is a series of failed attempts by the organisation responsible for cloning to prevent the clones coming face to face with one another. One underlying assumption of the film is that to have two clones existing simultaneously is socially unacceptable and unsettling. Although there are other more sophisticated explorations of cloning, such as *Boys From Brazil*, *The 6th Day* is the most recent example of cloning narratives where writers have touched upon a number of relevant issues surrounding human uniqueness and socially constructed boundaries of self/other, natural/cultural.

The use of twins for informing the cloning debates has been explicitly addressed in a David Teplica photographic exhibition, *Take Two: Identical Twins in Focus*, at the Wellcome Trust, London.[10] The exhibition consists of a number of photographs of identical twins which are intended to provide a 'down-to-earth perspective on the cloning debate' (Denna Jones, *BBC Online*, July 22 1999). Again, in keeping with the remit of other twin studies, the exhibition aims to explore ideas of sameness and difference and contribute to the genes-environment debate. Furthermore, to reiterate my earlier assertion that twins are ascribed a special status, the promotional literature states that identical twins are a 'fascinating cultural and scientific phenomenon'. Similarly, a symbolic-interactionist sociologist, Sadri (who is also a twin), has argued that twins provide an exceptional opportunity for exploring the social construction of reality (1994: 203-204). In a similar vein to David Teplica, Sadri has argued that twins disturb

[10] David Teplica is a plastic surgeon who photographs twins in his spare time. His initial interest in twins was fuelled by knowledge of his own twin brother who died in the womb (see http://www.wellcome.ac.uk/en/old/taketwo/MISexhTWOtwnBGDart.html [23/02/03].

our sense of human uniqueness in terms of human genetics and behaviour, and therefore, twins provide a site for examining these assumptions.

Although twins are deemed to be 'fascinating' and seem to challenge the borders of classificatory systems, both Teplica and Sadri align twins with 'nature' or the 'natural'. In asserting that identical twins can inform debates on cloning, the Wellcome Trust exhibition goes some way towards the naturalisation of clones (see pictures below). Depictions of twins within Teplica's exhibition aims to unsettle conceptions of human uniqueness in similar ways as do the computer generated clones associated with human cloning news stories. Furthermore, Teplica exhibits twins in poses that unsettles ideas of kinship relations in terms of socially sanctioned behaviours around sexuality and relatedness. Indeed, Teplica is quoted as saying 'they are very comfortable with each other – if one wants to bite the others jaw, the other is happy to oblige' (*BBC Online*, July 22 1999).

Source: http://www.wellcome.ac.uk/en/old/taketwo/MISexhTWOtwn.html [26/02/03].

Despite the 'special status' ascribed to twins and assumptions that they have 'special relationships' (e.g., exemplified by biting each others jaws!), they are, in the final instance, aligned with nature. Nature, it is argued, produces its own clones through the process of twinning and by extension, cloning merely mimics natural processes.

It is not surprising, then that the relationship between clones and twins is an area which was explored in the focus groups and interviews conducted as part of my research. In imagining a future with human cloning, many turned to twins as an existing phenomenon through which

they could explore their views. For example, when discussing what it might be like to be a cloned human F1M1 postulated:

> F1M1 It's hard, I mean, you've got identical twins walking the planet and they're independent individuals. They are not clones, because we wouldn't say that they're clones of each other, we'd say that they were identical twins. We don't tend to think of them as clones of each other, they are ... [interrupted]

Whilst F1M2, like many others in the focus groups, was concerned about the development of human reproductive cloning, when attempting to flesh out his concerns he formulates an argument characterised by ambivalence. However, the response to this by another member of the group confused matters further:

> FW1 Identical twins are natural humans.
>
> F1M1 They are natural humans, yeah.
>
> F1W1 They're part of nature. Cloning is, like, very much purposeful.

And then a few minutes later, F1M1 comes back to his comparison between twins and clones:

> F1M2 If a cloned child were to be a replica of a parent, erm, completely, in terms of the full process and thinks the same as the parent, the mannerisms are totally the same as a the parent, then I would have questions about whether that is normal. Because I would perhaps have to question whether that really is, it's almost a spiritual question. Whether that person is a real person with his own spiritual identity. And with twins were you know that each is an individual, as a clone I wouldn't know whether that really would be an individual. My guess is that it would be actually and, therefore, [laughs] I wouldn't have a problem because you're creating an individual being then (Patient-led Infertility Support Group, 19/06/01).

As with many other discussions that took place within the focus groups, cloning becomes unplaceable in the classificatory system. It is both like twinning, and therefore, natural, but also, due to being 'purposeful', unnatural. To a certain extent cloning was deemed to be non-threatening, even ordinary, since twins could provide a familiar reference point. On the other hand, whilst being *like* twins, clones were deemed to be something other, something beyond twinning which can be linked to the purposefulness of cloning. Twins are produced by chance, but clones are produced through conscious action. By this connection, clones are problematic because they are the result of controlling 'nature', whereas twins are produced by 'chance'.

What I have tried to make clear in this section, is how debates about human reproductive cloning are simultaneously about what constitutes a human being. Imaginings of cloned humans and their status in society provides in insight into both *what* are regarded as fundamental questions of life, such as what makes us human and what is the role of our genes in determining individuality, and *how* people formulate their ideas of such issues, such as what cultural resources are mobilised and what cultural categories are (re)negotiated. I have shown that people draw connections between clones and twins, and that such connections can operate to naturalise or denaturalise clones (and perhaps twins). To this extent, I have argued that reproductive cloning disrupts taken-for-granted assumptions about human uniqueness.

8.5 Challenging 'Natural' Reproduction: Human Cloning and IVF

The previous section introduced how, for some members in the patient-led infertility support group, the 'purposefulness' of reproductive cloning generates anxieties. In comparing twins with clones, 'nature-as-fate' (e.g., twins) becomes 'nature-controlled' and manipulated (e.g., clones). This understanding of nature-as-fate, however, is at odds with their own experiences of undergoing fertility treatment. IVF-related techniques are also 'purposeful' in that they intervene in the 'natural' reproductive process – for example, enabling people with fertility problems to have children or embryo selection techniques. To this extent, arguments that reproductive cloning is unsettling because it is 'purposeful' created an interesting dilemma for participants in the group.

In the following excerpt, participants in the patient-led infertility support group are engaged in a discussion about reproductive cloning as compared to existing fertility treatments:

> F1M1 That's the application that I can see next [reproductive cloning]. I think that its already been in some papers, erm, that for infertile couples, that if there's a problem you might decide that you could actually clone and have the result of a child in a natural progression of the womb. That its initial starting point is the cloning point. That to me, I feel is just like the next step along the IVF line. It's, you know, I can see that coming down the line. We're already sort of artificially fertilising the egg and sperm together. Cloning for infertile couples I can see, I see that further down the line.
>
> [Talking over one another about 'designer babies']
>
> F1M1 No, not so much a perfect human, just so that they could have a child if normal IVF techniques that we're using just now are not working.
>
> F1W2 Yeah well, that's the same thing as saying that we're going against nature if it's not happening naturally.

F1M1 Yeah, that's right. You're circumventing nature, that's happening already (Patient-led Infertility Support Group, 19/06/01).

Explicit references to 'nature' or 'natural', here, are appealed to as a relatively stable set of meanings and understandings against which interventions into reproductive processes are evaluated. In reflecting upon their uses of assisted conception practices, participants point out the contradictions of claiming that reproductive cloning is 'unnatural' since IVF already intervenes in 'natural' reproduction.

As the discussion progressed, it became clear that IVF has undergone processes of naturalisation and in doing so, shifted how participants construct 'natural' reproduction. Reproductive cloning, however, seemed to defamiliarise assisted conception practices. Subsequently, the accounts of participants reveals the processes involved in denaturalising and renaturalising meanings around reproduction. For example, in slipping between reproductive cloning and 'designer babies', participants raised their concerns that 'designer babies', such as using donated eggs from gifted musicians, limits 'nature' compared to assisted conception practices used by those in the group:

F1M1 That's [designer babies] something different to what we're trying to achieve here. We're using IVF techniques and that to circumvent a natural problem with the male or the female and given other circumstances there would be natural conception and the child would just grow up, you know. We're circumventing that because of technology that's been developed. I wouldn't say that's wrong. It's given my wife and I a chance to have what we want, and through no fault of our own there's a medical problem there. There's a blockage or a malformation of tubes or whatever. That's not anything that we did to ourselves, that's nature that has done that to ourselves. Is it, I don't know the question of whether it's wrong to be able to ... [interrupted]

F1W1 Thirty years ago there might have been somebody like you [indicating SP] actually asking practically the same questions about IVF.

[Agreement amongst group]

F1W1 And people would have, you know, it's not something that happens, it's not something that people think about. But now, twenty years down the line, goodness knows what will happen. Maybe there will be a clone.

F1M1 Maybe it's morally questionable whether to create that, let's say a designer child, purposely going along and taking eggs and sperm from particular gifted people and trying to create a child that will be gifted. I think that that would be morally wrong. But perhaps what we're going, I wouldn't say that. We're just wanting to have a natural child and be able to look after it (Patient-led Infertility Support Group, 19/06/01).

'Nature' here is something that both acts upon individuals and is acted upon by them. Infertility, for instance, is constructed as 'nature-gone-wrong', and in restoring people to their 'natural' state, assisted conception is 'nature-overcome'. In contradistinction to this, particular aspects of 'nature-as-fate' are held as a constant, such as the element of 'chance' produced from mixing the gametes of two people involved in a relationship. Reproductive cloning and 'designer babies' are regarded as morally reprehensible because, through embryo selection and manipulation, certain characteristics are screened in or pre-selected, thus determining the child's genes. To this extent, IVF practices are constructed as giving nature a 'helping hand' (Franklin, 1997: 96), enabling couples to have a 'natural' child, within a 'natural' family.

Central to the naturalisation of IVF is the mobilisation of what Koch has called the 'fairy tale model' (1992). In the above excerpt from F1M1, IVF is described as imitating nature through allowing a couple to have a child that is genetically 'their own' and 'technology' is the hero. The fairy tale model is akin to Franklin's argument that assisted reproduction is represented as 'natural science in the service of the natural family' (1993: 527). As I have shown so far in this chapter, a number of people questioned the 'naturalness' of reproductive cloning on the basis of kinship, reproduction and uniqueness. However, the quote from F1W1 illustrate that 'nature' is also understood as a shifting category with flexible boundaries that change over time. What constitutes 'nature' remains unresolved and yet 'natural' categories continue to serve as powerful reference points within the group discussion.

What has become clear from the above discussion (and in previous chapters) is the significance of embodied and lived experiences in shaping people's understanding of SCR and cloning. In terms of reproductive cloning, the views of members of the patient-led infertility support group were clearly shaped by their experiences of infertility and assisted conception practices. In the Diabetes support group, participants were less sympathetic towards any form of intervention into the reproductive process. For instance, during the discussion participants talked about distinctions between 'reproductive' and 'therapeutic' cloning. I then asked their views on using reproductive cloning for people who cannot conceive either with or without existing assisted conception techniques:

> DW1 But nobody has the right to a child. So I mean, I think there has to come a time that you accept that there's not going to be a family. And there are lots of children who are looking for homes, and I'm sorry, I just can't go along with this way of doing things. I think it's very wrong to fertilise people in their fifties. I genuinely think you're far too old to cope with young children and I think we need to redefine, people nowadays, they think you have a right to everything and you don't. There is no right.

Later on in the discussion, I ask what they think might drive developments in either SCR or cloning, to which DW1 responds:

> DW1 Demand from the public, especially women who seem to feel that at sixty they have the right to a child. I just can't understand that. I can't understand why anyone would want a child at sixty.
>
> SP What about if they were thirty and had fertility problems?
>
> DW1 Well, I think that's just unfortunate.
>
> SP Would that warrant cloning?
>
> DW1 No, I don't think it does.
>
> DM1 Although on demand, you've clearly got somebody who isn't infertile but want a particular sex of child or particular type of child or whatever and cloning would, I guess, provide an answer to that. A desire, not need, but desire.
>
> DW1 I think when you start on that sort of cloning you lose the human aspect. Everybody's very different. You know, there are disappointments in life and human beings just have to cope with these. They just have to, I think that's part of life. That's what forms your character and I really can't see why even at thirty you should be saying that I have the right to that, because you don't (Diabetes Support Group, 26/09/01).

Firstly, it is interesting to note that DW1 seems to confuse reproductive cloning with post-menopausal women using fertility treatments. I have assumed that this is the result of media reports on Antinori who has received a great deal of public attention for both reproductive cloning and for enabling a woman in her sixties to bear a child. A second point relates to DW1's view that childlessness is a 'disappointment in life' to be accepted. Any interventions into the reproductive process appear to be intensely unsettling for meanings around reproduction as well as for those around individuality and humanness.

During the interview with AC1M, who's wife has Alzheimer's Disease, he also talked about similarities and differences between reproductive cloning and existing assisted conception techniques. As in the Diabetes support group, I asked what he thought about using reproductive cloning for people who cannot conceive either with or without existing assisted conception techniques:

> AC1M A non-answer. I think that it's unfortunate that it would be the only alternative. Even in those cases I'm not sure that it should be used, I think that's too radical a process. I would really need to think about it a bit further to give a

> reasoned, considered answer, but my first reaction is it's too radical a process to use for such a common, or mundane, and I don't mean that word in an unkind sense. Obviously it's awful for the people but I would have thought that research, or the medical ability can get to cloning can find some half-way stage that is more appropriate to replace IVF or whatever.

Later on in the context of making a broader distinction between 'reproductive' and 'therapeutic' cloning, he says:

> AC1M Reproductive cloning I see as much narrower, just as important to the couple who stand to gain from it, a cancer sufferer or whatever, but it's still, reproductive compared to therapeutic is still very very narrow and it doesn't really, talking as a parent if you like, I'm not sure it really achieves the objective of a couple having their child which is a mixture of both of them, sort of thing. So you know, I'm just sort of uncomfortable with it (Alzheimer's Carer 1, 21/09/01).

In these accounts, reproductive cloning continues to be distanced from other forms of fertility treatment which are regarded as acceptable. As he clearly explains, he has not considered his views on reproductive cloning before the interview took place, but his first reaction points to the 'yuk factor' of cloning. Like the views of participants in the Sister-led infertility support group (see section 8.3), AC1M indicates that reproductive cloning is unacceptable as an assisted conception technique because reproduction occurs without the mixing of gametes.

In sum, this section has shown how views of reproductive cloning are mapped onto existing meanings attached to human reproduction and assisted conception practices. As a potential set of practices, reproductive cloning foregrounds meanings around 'natural' reproduction and explicitly reveals their contingencies and constructedness. What is understood as acceptable interventions into human reproduction becomes central to the debate and participants were able to trace shifts in meanings and categories. For instance, for those undergoing fertility treatment, reproductive cloning evokes a complex set of responses, revealing how existing assisted conception techniques are subject to processes of denaturalisation and renaturalisation which are intimately linked to embodied experiences of childlessness.

8.6 (Re)Constructing the Human Life Course

A fourth and final theme explored in this chapter concerns the way SCR and cloning-related developments unsettle conventional understandings of the human life course. This was an unforeseen theme that was not pursued as a key question across all focus groups and interviews, but emerged during discussions in some of the patient support groups. Both 'therapeutic' and

'reproductive' cloning practices were viewed as disrupting distinct stages within the life course, such as birth and death, albeit in different ways. By reflecting upon the ways in which people talked about SCR and cloning-related developments vis-à-vis their understanding of stages of the human life course (e.g. how and why they unsettle the human life course), I will highlight how, in this connection, 'nature' is socially (re)constructed and put to work.

In contemporary western societies the human life course is divided into distinct stages of life which are socially and historically specific (see Ariès, 1960; Pilcher, 1995): childhood, youth, adulthood, middle age and old age.[11] Transitions between these stages are often marked by particular events such as completing compulsory education, leaving home, employment, and procreation. Whilst there are significant differences in terms of biographical trajectories, there remains a dominant, normative narrative against which we each assess our own embodied life course.[12] Such life course events are punctuated by biographical disruptions which include unemployment, illness and/or death (Hareven, 1995: 129). Disruptions to the life course caused by illness are averted by medical science which offers drug and treatment regimes for managing or curing an increasing number of health conditions. By this connection, SCR and cloning-related practices are some of the latest developments to intervene in the human body and life course.

Before entering into a discussion of the accounts of participants in patient support groups, there are two key discursive strategies for understanding the relationship between new technologies and the human life course that are central to my analysis in this section. The first narrative corresponds to the co-existence of hopes and fears for (re)presenting new technological developments. New medical practices that intervene in human biology – ranging from organ transplants to NRTs – have evoked complex and ambivalent responses that often revolve around narratives of hope and fear (see Bloomfield and Vurdubakis, 1995; Mulkay, 1993; Turney, 1998). For example, Turney (1998) and Lock (2002) have shown that early developments in organ transplantation were regarded by some public groups as intervening in or manipulating nature. To this extent, medical research and practices are perceived to threaten the

[11] The boundaries between these categories, however, are not clearly demarcated and people's experiences of different life stages are diverse. Human life stages also 'vary significantly across cultures, classes, and historical periods' (Hareven, 1995: 125) and, therefore, cannot always be defined according to biological age (see Featherstone and Wernick, 1995). For instance, Tulle-Winton (2000) has referred to processes and experiences of infantalisation which occur during extended old age.

[12] Indeed, Harevan has argued that the transitions and events which constitute the life course have become institutionalised. The specific needs of the population at different life stages are dealt with by legislation and with the establishment of institutions, which in turn, affects the experience of individuals going through the life course (Harevan, 1995: 121-122).

'natural order' of life. This is not to suggest that people experience only fear in relation to new medical practices, but as the work of Turney (1998) and Lock (2002) illustrates in the context of organ transplantation, feelings of hope and expectation are also present. Furthermore, historical analyses illustrate that medical practices undergo processes of naturalisation and entrenchment, and views towards such practices are not fixed across time. This suggests that classifications of 'nature' also shift over time, dynamically incorporating scientific and medical developments into the 'natural order'.

Secondly, medical interventions into the human body are often framed as re-establishing the narrative of the human life course, thus *assisting* nature. This process of naturalising medical interventions through narratives of 'nature assisted' has been identified by Strathern (1992a, 1992b) and Franklin (1997, 1998) in the context of debates around new reproductive technologies. They have shown how dominant discourses in medical science construct interventions into human reproduction as a remedy to a problem in nature. For instance, infertility disrupts the naturalised life course of women who are unable to fulfil their 'natural' desire for motherhood and NRTs facilitate the events of reproduction and motherhood. NRTs, therefore, enable life's natural progression, tying gender roles to stages of the human life course. To this extent, the insertion of NRTs into conventional understandings of stages within the life course, converges with the rhetoric of hope discussed in previous chapters. In turn, categories of 'nature' are simultaneously reasserted and transformed – incorporating novel practices into narratives of the human life course.

Turning to the case-study in hand, SCR and cloning-related practices are recent examples of developments that threaten understandings of the 'natural' human life course. Reproductive cloning threatens to disrupt the human life course by enabling people to genetically reproduce themselves. Whilst such a position is founded on a genetic deterministic view of life, the birth of ones genetic copy disrupts the narrative sequence of the human life course. As already shown in section 8.4, participants within the cardiac support group suggested that reproductive cloning should only be permitted when the 'original' is already dead. Whilst the thrust of the point related to the issue of human uniqueness, a secondary reading of this hints at a disruption to the human life course. To 'purposefully' have two people alive who are at different ages (as opposed to 'natural' twins who are the same age and not-purposefully created) unsettles conventional understandings of the trajectory of the human life course.

To elaborate on this point a little further, I will briefly discuss how concerns that reproductive cloning disrupts the 'natural' life course are shaped by people's views of the relationship between

genes and individuality. Participants in the cardiac support group, imagined a future with cloned humans, discussing whether this allows people to 'live forever'. Suppositions that a person can live forever through exactly reproducing their genome, implicitly draw upon genetic determinist arguments, as illustrated in the following exchange:

SP But why do you think that somebody would want to clone themselves?

CM1 Because they're an egotist

CM4 Vanity

CM1 They want to live forever in one form or another

CW1 That's what I was saying earlier, somebody that wants to live on and on. (Cardiac Support Group, 18/07/01).

As this excerpt shows, some participants argued that reproductive cloning would appeal to 'narcissistic' individuals who want to reproduce their genome to 'live again'. This suggests that reproductive cloning is believed to extend the human life course because humans are determined by their genes. In order to avoid oversimplification and deconextualising people's quotes, however, it is important to note that the broader context of the cardiac support group discussion revealed a far more complex view of the genes-environment debate than is presented above. Whilst there was often a recourse to genetic determinism and such explanations were sometimes privileged, a number of participants argued that humans are the sum of complex interactions between ones genes and the environment.

A further point to raise on the implications of reproductive cloning, corresponds to the quote from DW1 in the Diabetes support group in section 8.5. As already discussed, DW1 links reproductive cloning with the use of fertility treatments to enable post-menopausal women to have children. In connecting these two issues together, DW1 points to an underlying concern that stages within the life course are being transgressed by such practices. The biological capacity of women to bear children is reinstated via science and technology, and this unsettles taken-for-granted categories associated with different stages of the life course. According to DW1, motherhood marks an earlier phase in women's life course, and should not be available to women during their 50's.

Potential applications of SCR and 'therapeutic' cloning also unsettle taken-for-granted classifications of the human life course. As outlined in previous chapters, one of a central aims presented by SCR-advocates for legitimating this area of research (see chapters 3 and 5), has

been the potential to develop treatments or cures for diseases such as Alzheimer's and Huntington's - diseases associated with ageing.[13] SCR, it is argued, holds the potential to intervene in biological processes currently linked with the ageing body, such as dementia and other conditions related to cell degeneration. Aims include the ability to replace damaged tissues or nerve cells and, ultimately, to grow replacement organs. If SCR and cloning-related practices are successful, then human life expectancy could extend beyond what is currently possible.

In the cardiac support group, this issue of extending life expectancy raised a number of concerns that I will address in turn. Very early on in the discussion, CM4 outlined his hopes for 'therapeutic' cloning and the ability to grow replacement organs. Drawing on his experiences of receiving a heart transplant, CM4 describes the complications involved in taking immunosuppressant drugs, such as kidney damage and organ rejection problems. In responding to this, CW2 expresses her anxieties:

> CW2 But what if somebody tried to use it for, you know how they go in for all these operations, for face-lifts and this and that. If they wanted to prolong a good life, if it got in the wrong hands, if they made money out of it that way. That I don't, that's why I'm not sure about cloning. If you look at medical, whether it's necessary, but if it went too far and you know, somebody else thought "oh, I'm fine otherwise and I've got a good life and I've got loads of money", and that's it, "I've got loads of money and I just wanted - if something's failing replace it" (Cardiac Support Group, 18/07/01).

There are three elements interwoven in the above quote. Firstly, 'fixing' parts of ones body that begin to fail with age is regarded as crossing the line of acceptability. Secondly, CW2 distinguishes between cosmetic and medical uses of medical interventions. Here, her concerns are not with extending life *per se*, but instead seem to lie with extending 'youth'. There is a subtlety to her views: repairing body parts to save lives (e.g. heart transplantation) is acceptable, but repairing body parts to avoid problems associated with ageing (e.g. wrinkles) are unacceptable. Thirdly, transgressions of the human life course were further compounded by economic factors. In relation to healthcare access and provision of SCR and 'therapeutic' cloning, CW2 compares these to existing medical practices which are 'therapeutic' but are also used for commercially lucrative applications (i.e. cosmetic surgery). Such quotes provide an

[13] Research conducted by pharmaceutical companies such as Geron, one of the leading companies involved in developing SCR and cloning-related developments, are striving to understand, control and even reverse processes currently associated with the ageing body, such as cell degeneration. Under the rubric of regenerative medicine (a term that has emerged in the US political context to refer to eSCR and 'therapeutic' uses of the cloning technique), scientists working in the field of SCR and other advocates have argued that this research has the potential to eradicate many diseases associated with ageing.

insight into the anxieties felt by some participants – that medical therapies derived from SCR and cloning will not be available on the National Health Service. Here she fears that only those who can afford such therapies will be able to extend their life expectancy.

One of the Alzheimer's carers, AC2W, outlined similar concerns about SCR and cloning-related developments. At the beginning of the interview, I asked her about her motivations for participating in my research. She then began by explaining that her sister has Alzheimer's disease and that this area of research sounds promising as a source of medical treatments and cures. AC2W then goes on to say:

> AC2W My first words were, no, what sort of check, what sort of holds are there going to be on just going your own thing? What, it's not control it's what is the ethical borderline? (Alzheimer's Carer 2, 03/10/01).

I then asked whether she had any immediate thoughts on what problems might arise:

> AC2W I don't mind if somebody is sick, they're sick. It's more how it could filter through into other things where you could use cloning. You know, a second and third stage where you could use these sort of things for cosmetic reasons or, that's all. It's unethical isn't it? (Alzheimer's Carer 2, 03/10/01).

Like CW2 in the cardiac support group, AC2W distinguishes between medical and cosmetic uses of SCR and cloning. Again this suggests that there is a perceived difference between extending a person's life who would otherwise die through illness and extending the signs of youth that cosmetic surgery brings.

As illustrated throughout this thesis, developments in SCR and cloning have generated contradictory 'public' responses. Whilst on the one hand, the potential of SCR to develop therapies for as yet incurable conditions was deemed to be a positive thing, on the other, many people also expressed fears and anxieties. In the following excerpt, participants in the cardiac support group are talking about potential developments in 'reproductive' cloning, which CM1 argues will inevitably take place:

> CW2 Well, well I'd be against it.
>
> CM1 Well there are rumours that it's already happened or it's in the process of happening.
>
> CW2 I mean the thing is, you're born to a man and a woman, you know, you're an individual person, you don't want to reproduce you, yourself. At I least I wouldn't. I mean, I'll take my life span and I'll go and that's it. You know,

you're sort of like flowers, you come, you grow and then you die. I mean this idea of having something artificial.

CW1 But I thought we said, say an idea such as organs – we're not going to die.

CW2 Yeah I suppose so. It's just, I don't know (Cardiac Support Group, 18/07/01).

The analogy with flowers provides an interesting insight into how SCR and reproductive cloning unsettles the 'natural' life course. Whilst CW2 begins by talking about reproductive cloning she slips into 'therapeutic' cloning, applying the same sense of unease to both. It is also notable that a cloned human is regarded as 'artificial' – a point that relates to the earlier section on human uniqueness (see 8.4).

As the discussion progressed others in the group were arguing that 'reproductive' and 'therapeutic' cloning differed because the latter would, potentially, produce organs or tissue for people requiring them. CW2 was also uncomfortable with these suggestions:

CW2 It just seems disgusting to me, I'll be quite honest it really does.

CM4 We're not talking about whole cloning here, but maybe for organs

CW2 Yeah, maybe for organs, but to clone a person.

CM4 You don't want to be doing it for whole humans, but you want to ... [interrupted]

CW2 [interrupting] Well if it's going to be helpful. To be honest I would rather you don't have anything. You would just live your life, you die and that was it. I mean I'm grateful.

CM1 Well lets take it one step beyond that. You've got a child of three which is dying because of heart failure. If they could clone a heart and transplant it and that child lives until it's ninety-three.

CW2 Yeah, it's a very difficult dilemma from my own point of view I think.

CM1 But what if that child happens to be Einstein or the second one?

CW2 Yeah well. Yeah, I do sometimes think that you're put on this earth and you live a span and then you die and that's it, but erm ... [interrupted]

CM1 [interrupting] Well we've been interfering with that side for ... [interrupted]

CW2 [interrupting] Oh yes, I mean all of us progress. If you don't progress you don't live it's as simple as that. I could have been dead by now, you know, but I had a heart operation.

SP Do you see SCR and cloning as part of progress?

CW2 No, I honestly don't. I think it's disgusting, I honestly do (Cardiac Support Group, 18/07/01).

This exchange, once again illustrates participants' contradictory responses to SCR and cloning-related developments. Throughout the discussion CW2 struggled over the stem cell issue, with her ambivalence expressed according to both hopes (in the form of scientific progress) and fears. On the one hand, she does not support the use of the cloning technique for medical therapies. Even when CM1 uses the emotive example of a child requiring an organ transplant, her response remains acutely ambivalent. At the end of the exchange, however, she states that without a heart operation she would probably have died, thus illustrating that her embodied experiences of illness and medical interventions did not wholly determine her view of SCR and cloning. Overall, it seems that CW2 was not against medical interventions, but against the use of 'cloning' for both 'therapeutic' and 'reproductive' purposes. Because 'cloning' evoked the 'yuk factor' and unsettled her understanding of the 'natural order', CW2 mobilises a version of 'nature' that renders her own experiences of health and illness 'unnatural'. The processes of denaturalisation and renaturalisation that occurs during the above excerpt exemplifies the complex interplay between CW2's embodied biography and her understanding of 'nature'. Meanings of SCR and cloning are never settled, but remain unplaceable in the classificatory system – hence, abject.

When considering whether SCR and cloning-related practices are 'unnatural', a number of members in the patient support group drew parallels with other medical practices. For instance, in the Huntington's disease support group one woman compared reproductive cloning to the fears generated by the development of Chloroform:

HW I was reading about Simpson who first used Chloroform. The medical profession and the Church throughout the world said it was evil and that man was made to suffer and that it was actually cowardly to have an anaesthetic. So all these new things that come out, people, and that was the medical profession and the Church throughout the world.

HW We've come a long way in just over a couple of hundred years so who knows in two-hundred years what we'll think about cloning.

HW It's like these films, you know, it's like having ... [interrupted]

HW [interrupting] Frankenstein.

HW ... [continuing] Yeah, that's right. It's like it coming to life (Huntington's Disease Support Group, 31/10/01).

Similarly, in other groups, participants talked about medical practices that used to be regarded as against nature, or against God but today are normalised, including IVF, organ donation and travelling to the moon. What this illustrates, is how during the focus group discussions participants actively denaturalised and renaturalised a range of scientific and medical practices by placing them in a broader social and historical context. One function this seemed to serve in the discussions, was to naturalise SCR and cloning. As I have shown throughout chapters 6 to 8, CM1 argued very strongly in favour of SCR and 'therapeutic' cloning. And in the group context where CW2 believed that such developments go against nature, he argued:

CM1 Life's too short no matter how long it is. And if it will prolong life, I'm all for it.

Later on he states:

CM1 I want to live until I'm at least 107 (Cardiac Support Group, 18/07/01).

Rather than being unsettled by the potential to extend life, CM1 emphatically embraces such developments. As in many of the discussions in the cardiac focus group, CM1 stood out as the 'joker' as well as holding affirmative views for SCR and related medical applications. For CM1, nature is a shifting category that has always been reinvented as science, technology and medicine have progressed. Therefore, to argue that SCR and cloning - whether for 'reproductive' or 'therapeutic' purposes - are, or will continue to be regarded as 'unnatural' and unsettling understandings of the life course, was counterpoised with his knowledge of historical cases. As indicated above, such arguments were not specific to the cardiac support group but also arose within many of the other discussions.

What I have shown in this section is how existing understandings and discourses of the human life course are mobilised when considering ones views of SCR and cloning-related developments. Whilst there are a set of meanings associated with ageing, or moments within the life course, these intersect with other naturalised sociocultural categories such as gender and motherhood. As I have shown, 'reproductive' cloning seems to, primarily, unsettle conventional meanings around the trajectory of the life course - a view deeply embedded in genetic essentialism. SCR and 'therapeutic' cloning unsettle understandings of the life span by opening

up the possibility to extend life beyond what is currently regarded as 'old age'. Relating to this, it also holds the potential to redefine the experience of old age, 'fixing' tissues and organs as they degenerate. A further dimension to SCR and cloning developments is the potential to treat a wide-range of diseases and conditions, thus, having implications for a large number of people. For sociologists then, it is important to continue to investigate both the various applications of SCR and cloning that impact upon the human life span, but also people's views of such developments.

8.7 Conclusions

Framed around four themes – kinship, human uniqueness, reproduction and the human life course – this chapter has highlighted how categories of 'nature' are mobilised, negotiated, contested and reconstructed in people's accounts of SCR and cloning. Here I have illustrated how classificatory systems operate according to complex borrowings between binary categories. In my analysis 'nature' is used as both a category and repertoire in itself, as well as a meta-category for classificatory systems. That is, binary categories such as human/non-human, self/other are naturalised categories, constituted through a variety of sociocultural processes.

As in previous chapters, I show how participants' views are shaped, but not determined, by their embodied and lived experiences. What is particularly interesting here, is that the issues raised in the discussions denaturalised medical practices used by some participants. For example, in section 8.5 I show how participants in the patient-led infertility support group reflect upon IVF practices, considering whether they are already 'going against nature' (F1W2). Similarly, within the cardiac support group, CM4 compares SCR and 'therapeutic' cloning with organ transplantations and CW2 connects 'cloning' with cosmetic surgery. In all instances, the contingencies of 'nature' are made visible and explicit, and cultural categories are put to work in complex and contradictory ways. Although binary categories remain powerful as discourses for ordering meanings, understandings and knowledge, 'nature' and its 'other' (e.g., science, progress, technology, culture) are co-produced and dialogic, and their boundaries are permeable.

I now want to return to the significance of the theoretical approaches introduced in sections 8.2.1 and 8.2.2 in this chapter. Following on from the approach of Franklin *et al.* (2000), I have illustrated how 'nature' as a category is continually (re)produced in a dynamic process. Analysis of people's accounts of SCR and cloning exemplify how 'nature' is never fixed, always shifting, contested, and renegotiated and often 'held' paradoxically. In reflecting upon my analysis of empirical data, Franklin *et al*'s conceptual approach is useful for capturing how 'nature' operates

through processes of naturalisation, denaturalisation and renaturalisation (2000: 19). This processual model of 'nature' refers to a dynamic set of techniques and practices (e.g., discursive and political) through which categories are produced, and where such categories are embedded in sociocultural contexts. A further important point corresponds to the durability and pervasiveness of 'nature' as a powerful category and set of discourses. What my analysis has confirmed, is the paradox of cultural categories, that is, their immutability and their malleability.

Once 'nature' is understood to be achieved through processes of naturalisation, denaturalisation and renaturalisation, then abjection becomes a helpful concept for capturing specific moments within that process. As outlined in section 8.2.2, abjection relates to ideas and objects at the boundaries that threaten to disrupt the 'natural order'. In the context of SCR and cloning developments, abjection is when novel practices are yet to be categorised, when 'nature' is denaturalised. Overall, the accounts presented in this chapter illustrate that SCR and cloning developments offer new ways for thinking about human reproduction, kinship relations, the life course and human uniqueness. Because these practices unsettle the 'natural order', some people articulated specific anxieties, such as Ian Wilmut's concern that reproductive cloning would generate problems within the family that may negatively impact upon the clone (see 8.3). Others expressed a more general sense of unease, such as CW2 in the cardiac support group who refers to cloning developments as 'disgusting' (see 8.6). Threats to the natural order also generated discussions that contextualised 'nature' according to historical specificities. For example, in the Huntington's disease support group, participants connected 'reproductive' cloning with the development of anaesthetics (see 8.6). Here, naturalised medical practices (use of anaesthetics during operations) were denaturalised, connected to 'reproductive' cloning, and then both were renaturalised.

What is interesting in all of these examples, is that people showed an awareness of 'nature' as malleable, as a category to be put to work in complex and contradictory ways. However, as I have shown, it is when 'nature' is cross-referenced with other categories – e.g. between age, gender and motherhood in NRT's or 'reproductive' cloning (see DW1 in section 8.5) – that constructions of 'nature' is a powerful discursive repertoire. Whilst categories such as gender, age and motherhood are flexible, when cross-mapped they limit the range of meanings, understandings and possibilities. To return to the concept of abjection, this is potentially a useful political concept to open up critical spaces within the SCR and cloning debates. If we harness this "non-category" or "third category", then as social scientists, I believe, we can deconstruct the naturalness of nature as well as contribute to theoretical models for understanding how 'nature' is constituted in specific contexts. My analysis of people's accounts of SCR and cloning

in this chapter has shown how 'nature' is explicitly questioned, negotiated and put to work, revealing its constructedness. As a limit case, existing at the borders of classificatory systems and still undergoing processes of naturalisation, SCR and cloning points to new ways of ordering and thinking about categories such as human, life, reproduction, ageing and kinship. By this connection, as social scientists, we need to continue developing more sophisticated ways for theorising and modelling the implications of new practices in science, technology and medicine.

CHAPTER IX

Conclusions

Rather than simply summarising the thesis, in this chapter I will attempt to pull together some of the threads that cut through my analysis for a fuller picture of its scope and magnitude. Because of the political aims of this thesis – to give voice to marginalised groups – I start by extrapolating from my analysis some policy implications for SCR and cloning, as well as for wider relations between scientists and public groups. In the second part of this chapter, I will offer some thoughts on the significance of this thesis for social science theories and concepts.

This thesis has been written with the express aim of explicating some of the ways SCR and cloning is being constructed by both scientists and other relevant social groups. To do this, I have mapped a number of recurrent themes that have emerged in the parliamentary debates, and identified relevant social groups whose voices, whilst rhetorically invoked in the SCR and cloning debates, have been systematically marginalised. I have conducted in-depth interviews with scientists working in the field of SCR and/or cloning, focus groups with patient and infertility support groups, and interviews with two carers for people with Alzheimer's. In these interviews and focus groups, I allowed participants to discuss issues surrounding SCR and cloning, generating their own sets of questions, problems, hopes and fears. An overarching aim was to move beyond the polarised debates – as presented in Parliament and related policy documents – and to problematise dominant accounts of SCR and cloning.

9.1 Practical and Policy Considerations

In keeping with the cPUS approaches of Wynne and others, the thesis challenges traditional PUS models that characterise 'public' anxieties towards novel areas of science, technology and medicine as *mis*understanding. I have thereby contributed to existing research that emphasises the need to capture the range of local contexts and embodied experiences that shape the views of scientists and non-scientists alike. If matters of 'public' (mis)trust are to be addressed, the epistemological assumptions underpinning what counts as 'knowledge' and 'expertise' in models of science-public relations used for policymaking and communication activities must be reconsidered. This is an important endeavour precisely because democratic, transparent and inclusive public debates call for scientists to be reflexive about the social and cultural dimensions of their own activities and knowledge, as well as those of the public. As I have noted

in Chapters 4, 5 and 6, both scientists and publics are aware of the changing cultural context within which science now operates. That is, focus group participants no longer regard science as a homogenous enterprise but, made up, instead, of multiple voices from within and outwith the 'walls of the palace'. Thus, scientists are increasingly viewed with scepticism by publics within a society that defines 'risk' in a more reflexive, provisional and open-ended fashion.

From this standpoint, Chapter 5 shows that scientists appear to be moving towards reflexive models of PUS - for instance, including the views of some patient groups, and ascribing a degree of 'expertise' to embodied experiences of health and illness. Science, in this sense, appears to be moving away from the deficit model of PUS that positions scientific rationality as the only valid knowledge, or what Irwin and Wynne call, 'the arrogance of a supposed "higher rationality"' (1996c: 221). Such moves towards a reflexive science, however, need to be further interrogated and treated with caution because, I suggest, reflexive processes do not necessarily translate into reflexive outcomes. This can be further substantiated by three points. Firstly, only some patient groups are included (those that have publicly supported eSCR, in particular). Secondly, the inclusion of such groups simplifies what are rich, complex and ambivalent accounts of SCR and cloning. Thirdly, as I have shown in my analysis of the parliamentary debates, patient groups have been rhetorically invoked by pro-eSCR-advocates and yet have had no direct input into the debates. I will return to this point again later. What I have revealed is how, in the name of reflexivity, scientists accounts have tended to contribute to polarising the debates, positioning individuals and groups as either for or against SCR and undermining the potential of reflexivity. In this process, the nuances of people's views are lost and their identities delimited. People with diseases and conditions that may be treated with stem cell therapies are claimed to be wholly in favour of eSCR, unless, of course, they are politically aligned with anti-abortion groups.

The exclusion of public ambivalence and other meanings that fall outside ready-made schemas, is, I believe, central to the current impasse in science-public relations. Ambiguous or contradictory understandings do not fit into the current policy and decision-making processes, and are of little use in public debates that tend to resort to the language of certainty and risk management. As far as science policymaking is concerned, what is needed is for scientists and others involved in policy to develop new and sophisticated ways for both including and hearing public views. Such practices might involve institutional and cultural changes to the ways in which policies are formed and implemented to broaden debates. Indeed, as I have argued in Chapter 4, institutions such as the *Wellcome Trust*, *Royal Society* and advisory bodies such as the *Human Genetics Commission*, are already developing innovative public engagement practices.

Citizens juries, focus groups and 'public' meetings are becoming commonplace as laudable practices, 'the public' have become 'the publics', and interest groups now occupy a central place in policymaking contexts. And yet, as noted in Chapters 6 and 7, whilst this certainly constitutes a step in the right direction for facilitating wider discussion between scientists and other public groups, some of the most difficult questions raised by publics continue to be omitted. The implications of this omission are far-reaching and can be gauged by a brief revisit to the views of participants in patient and infertility support groups.

In Chapter 7 I revealed that people undergoing fertility treatments are unwilling to donate 'viable' embryos for SCR. When still trying to conceive a child, 'viable' embryos are not 'spare' embryos, but are associated with hope – as *potential* children. To claim, as many eSCR-advocates have, that people undergoing fertility treatment are willing to donate embryos for SCR, fails to attend to people's embodied understandings of embryos, and a pervasive sense of scepticism towards science and scientists. Across all patient and infertility support groups, participants raised a number of questions around trust and risk that were largely omitted within parliamentary debates and in core-eSCR-scientists' accounts. Such issues included trust in regulatory mechanisms, anxieties regarding the potential exploitation of this area by 'unscrupulous' scientists (e.g., the slippery slope from 'therapeutic' to 'reproductive' cloning) and concerns about the future direction of this area of science. These fears were underpinned by an awareness of the nature of scientific research in today's context, understood as multi-vocal and institutionally linked to other social spheres, such as commerce and politics. However, I have tried not to fuel claims that there is an 'anti-science' climate in the UK. Instead, I have attempted to relay the tension between hope and fear that persists in people's accounts of SCR and cloning. Therapies derived from SCR and cloning-related developments were certainly received with expectation, but this should not be translated as an unquestioned 'demand' by pro-eSCR advocates.

Whilst a 'magic bullet' solution to the problems surrounding public ambivalence, policy and decision-making processes does not exist, a number of changes to facilitate wider inclusion can be suggested, following existing cPUS studies. Firstly, public consultation exercises have to be reconsidered, for participants need to be able to generate their own questions and issues, posing policy problems and solutions. Such exercises should not be conducted once policies are in place or after scientific research is already underway, but should allow public views to shape, what Wynne calls, 'front-end innovation commitments' (2002: 463). Indeed, my analysis of the SCR and cloning debates shows that publics were excluded from 'front-end' decision-making

processes, and marginalised during debates corresponding to 'back-end' decision-making processes.

The meaningful inclusion of plurality, complexity and uncertainty into policymaking processes cannot be achieved overnight – the wealth of studies that have already attempted to provide solutions to this problem is evidence of the weight of such a task. This is made all the more difficult because of the current tension between 'tradition' and reflexivity' outlined in Chapter 4. Here, scientists operate between reflexive accounts of expertise, incorporating plurality and including alternative forms of knowledge, whilst also appealing to traditional boundaries between binary categories such as expert/lay and science/publics. However, scientists' apparent willingness to engage in public engagement activities and the flexibility of boundaries between such binary categories, points to an opening for social scientists and public groups to intervene and open up the SCR and cloning debates.

Finally, given the centrality of trust in science-public relations, the management of the SCR and cloning debates by eSCR-advocates has been an obstacle to meaningful dialogue. It was not only alternative voices within non-science groups that were marginalised, but also those within science, such as those of scientists working on adult SCR (see Chapter 3). For example, within the parliamentary debates and in scientists' accounts, eSCR advocates mobilised scientistic discourses to argue that adult SCR are less likely to develop therapies questioning the validity of the claims of scientists working with adult stem cells. In dominating and effectively managing the SCR and cloning debates, the voices of scientists working with adult stem cells were largely omitted or presented with scepticism by eSCR advocates. Similarly, different forms of knowledge need to be allowed to flourish alongside scientific knowledge, and recognised as legitimate ways of understanding. Indeed, discussions with patient groups that took place for this PhD indicated that the exclusion of 'non-scientific' knowledge further generates a sense of powerlessness and mistrust. When publics no longer regard science as isolated from other social spheres and when risks generated by science and technology are understood to be intimately tied to the wider social context (see Chapter 8), then to continue to exclude these dimensions from public debates continues to propagate elements of the deficit model of PUS.

9.2 Relevance to the Social Sciences

The crosscutting themes identified in this thesis were informed by the theoretical, conceptual and methodological approaches of sociology, cultural studies and STS. These disciplinary approaches enabled me to identify key and recurrent themes in people's accounts of SCR and

cloning, and in turn, to develop a sophisticated understanding of the social and cultural dimensions of such developments. At the same time, the data generated in my analysis of parliamentary debates, scientists' discourses and within focus groups and interviews with non-scientists, feeds back into our understanding of themes and concepts such as risk, trust and binary categories. Many of the themes have been difficult to separate out from one another, and, subsequently, excerpts from interviews and focus groups contain a number of themes that could have been analysed differently by shifting my emphasis. Rather than trying to further separate the key themes that were central to my analysis, in this final section I will attempt a 'meta-analysis', highlighting the significance of bringing together risk, trust, reflexive modernisation, and boundary work, for investigating the discursive construction of SCR and cloning.

'Risk' has been a central theme in the SCR and cloning debates – implicitly present in my analysis and sometimes emerging as an explicit theme. As argued in Chapter 4, 'risk' is endemic in modern Western societies, increasingly pervading social, cultural and political practices. Here, I discussed the approaches of Beck and cPUS that have illuminated the role of risks in generating transformations in contemporary society. Similarly, the concept of risk itself is undergoing transformations, including our understanding of what risks are, how they are generated, who generates them, what their implications might be and how we experience them. Analysis of these transformations has led people such as Irwin (1995), Irwin and Wynne (1996 b, 1996c), Wynne (1988, 1992, 1995, 1996, 2002) and Van Loon (2002), to argue that we need to attend to the various elements that constitute modern understandings of risks. Here, it is imperative to investigate how risks are constituted, the discursive repertoires mobilised, which voices and discourses gain legitimacy and which become marginalised.

My analysis of the SCR and cloning debates has contributed to such approaches, confirming the need to explore the cultural dimensions of risk definitions in public discourses. To continue to define risks according to methods of calculation, measurement and avoidance, misses the point of how many public groups understand and experience risks. Analytically, it has been important to mobilise a nuanced understanding of 'risk' to capture the ambiguity, indeterminacy and unquantifiable nature of risks in people's accounts of SCR and cloning. In contradistinction to traditional risk evaluation methods, my research captures how people articulate risks and negotiate their implications vis-à-vis their everyday lives. For example, in patient and infertility support groups, participants mobilised cultural resources such as film and literature, or historical case-studies of the introduction of novel practices in science, technology and medicine (see Chapters 6, 7 and 8). Here, the use of focus groups and in-depth interviews were effective data collection methods for illustrating that cultural idioms and knowledge must be recognised as

valid knowledge of risk. In doing so, this methodological approach helps to sharpen 'risk' as a concept within the social sciences, showing its implicit ambiguity and multivalency.

Closely related to risk, are the themes of trust and uncertainty which have also received attention from those working within the sub-field of cPUS (see for example, Brown and Michael, 2002; Irwin, 1995; Szerszynski, 1999). My analysis of publics' accounts of SCR and cloning debates, reveals the centrality of trust and also its elusiveness. Scientists were never fully trusted, but trust was never entirely absent; instead, people's views were characterised by ambivalence. Such understandings of science and scientists indicate that trust is never fixed or won but that actors are engaged in 'trust' relations that need to be continually maintained. A further contingency in people's understanding of the trustworthiness of scientists working on SCR and cloning is the broader social, economic and cultural context within which science operates. As noted in the previous section (see 9.1), perceived connections between science and other social spheres generates public scepticism towards science and scientists. Such scepticism is equally applied to those other social spheres and their related expert systems such as commerce, the media and politics (see Chapter 6). The complexities of (mis)trust in people's accounts of SCR and cloning highlights the need for a model of trust in social science research that sensitises the researcher to public ambivalence and contradictions and the embodied and lived experiences that shape such understandings.

Underlying the current concern with risk and trust within social science and, indeed, government related decision-making bodies, is the broader context of reflexive modernisation processes. In Chapter 4 I introduced Beck's theory of reflexive modernity as an important conceptual tool for capturing the paradoxes inherent in contemporary society – the tension between 'reflexive' and 'non-reflexive' (also referred to as 'traditional' or the 'deficit') models of PUS. This approach marks the convergence between Beck's *Risk Society* thesis (1992) and the work of Wynne and others conducting cPUS research. As discussed in Section 9.1, the paradoxes of reflexive modernity are a central feature of my analytical framework for exploring constructions of SCR and cloning precisely because it problematises rather than reifies binary categories such as expert/lay, science/society, scientists/publics. In contributing to theories of reflexive modernity I have confirmed how tensions between 'reflexivity' and 'tradition' are visible in people's meanings and understandings of SCR and cloning-related developments. My analysis illustrates how reflexivity has seeped into the discourses mobilised by core-eSCR-scientists, members of patient and infertility support groups, and speakers within parliamentary debates. The social and cultural dimensions of the scientific enterprise are visible, and the social constructedness of categories such as 'science', 'expertise' and 'knowledge' are openly discussed.

This brings me to the penultimate crosscutting theme – boundary work (Gieryn, 1983, 1995). In Chapter 5 I explored how core-eSCR-scientists engage in boundary work in order to construct their work as credible and legitimate, thus asserting themselves as 'experts'. The importance of rhetorically separating eSCR from reproductive cloning or distinguishing stem cells from embryos, for instance, exemplifies how boundary work serves to shore up traditional constructions of expertise, constructing core-eSCR-scientists as particular sorts of actors (i.e. acting ethically). Processes of boundary work *also* reveal the flexibility of boundaries and that demarcations between categories are socially constituted. In other words, scientists do not negotiate between fixed, monolithic categories of science/society, expert/lay, scientists/publics, but actively construct, negotiate and reconstruct these binary categories. My analysis of scientists' discourses extends the 'boundary work' approach of Gieryn (1983, 1995), revealing that while scientists continue to appeal to such boundaries, they simultaneously blur them, making it increasingly difficult to distinguish between scientists/publics, expert/lay, inside/outside. Here, the boundaries between categories are shown to be both malleable and durable, and sometimes fuzzy. This again illustrates the underlying tension inherent in processes of reflexive modernisation between traditional and reflexive models of PUS.

The paradox identified above – the malleability and durability of boundaries between binary categories – is extended, in my analysis, to understand the (re)negotiation of categories around 'nature'. Like core-eSCR-scientists, participants within patient and infertility support groups engaged in boundary work when constructing understandings and meanings around SCR and cloning. A key distinction here is that when scientists engaged in boundary work they tended to limit the SCR and cloning debates, whereas people in focus groups and interviews did so to open up these debates. Ordered around four key themes – kinship, human uniqueness, reproduction and the human life course – I illustrate how developments in this area of science and technology unsettle cultural categories. In other words, SCR and cloning are shown to generate anxieties because they are risks to the stability of conventional cultural categories. People's negotiation of these risks, however, are reflexive to the extent that participants do not simply appeal to such categories, but actively put them to work in complex and contradictory ways, revealing the contingencies of 'nature'. What is interesting here, is the sense of uncertainty embedded in people's understanding of 'nature', seen as transitory – shifting across time and space – and yet remaining a powerful discourse for ordering and understanding SCR and cloning-related developments.

SCR and cloning, then, raise a number of issues that are interesting to the social sciences. The potential of this area of science and technology to redefine meanings and understandings of cultural categories poses difficult questions for social scientists to which there seems no simple response. Social scientists must actively engage with dominant actors (e.g., core-eSCR-scientists and people involved in policymaking) to identify relevant areas for making critical interventions, such as policymaking processes and the future direction of this field. Informed by appropriate theoretical and conceptual tools, it is also essential to conduct empirical research that explores the range of meanings and understandings formed by different social groups – both scientists and publics. In the face of fast-paced, innovative scientific developments, social scientists are required to develop equally innovative conceptual and methodological research strategies. But with so much at stake, we must strive towards a democratically grounded reflexive (social) science.

Bibliography

Adam, Barbara and Van Loon, Joost (2000) 'Introduction', in Adam, Barbara, Beck, Ulrich and Van Loon, Joost (eds) *The Risk Society and Beyond: Critical Issues for Social Theory*, London: Sage.

Anderson, Alison (2002) 'In Search of the Holy Grail: Media Discourse and the New Human Genetics', *New Genetics and Society*, vol. 21, No. 3, pp. 327 – 337.

Anon. (1998) 'Time to Act on Cloning', *Financial Times*, Jan 11 http://globalarchive.ft.com/globalarchive/articles.html?print=true&id=980111002691# [29/05/01].

Anon. (2000) 'UK developing anti-science culture' *BBC News Online*, 17 Nov http://news.bbc.co.uk/hi/english/sci/tech/newsid_1028000/1028911.stm [20/11/00].

Appleyard, Bryan (1999) *Brave New Worlds: Genetics and the Human Experience*, London: Harper Collins.

Ariès, Philippe (1960) *Centuries of Childhood*, Harmondsworth (reprinted 1986), Middlesex: Penguin Books.

Arksey, Hilary and Knight, Peter (1999) *Interviewing for Social Scientists*, London: Sage.

Barnes, Barry and Edge, David (1982) *Science in Context: Readings in the Sociology of Science*, Milton Keynes: Open University Press.

Bauer, Martin and Gaskell, George (eds) (2002) *Biotechnology: The Making of a Global Controversy*, Cambridge: Cambridge University Press.

BBC Online (1999) 'Scientists Clone A Goat', Apr 27, http://news.bbc.co.uk/1/hi/sci/tech/329107.stm.

BBC Online (2000) 'UK 'Developing Anti-Science Culture', Nov 17, http://news.bbc.co.uk/1/hi/sci/tech/1028911.stm.

Beck, Ulrich (1992) *Risk Society: Towards and New Modernity*, London: Sage.

Beck, Ulrich (1994) 'The Reinvention of Politics: Towards a Theory of Reflexive Modernization', in Beck, Ulrich, Giddens, Anthony and Lash, Scott (eds) *Reflexive Modernization: Politics, Tradition and Aesthetics in the Modern Social Order*, Cambridge: Polity Press.

Beck, Ulrich (1995) *Ecological Politics in an Age of Risk*, Cambridge: Polity Press.

Beck, Ulrich, Bonss Wolfgang and Lau, Christoph (2003) 'The Theory of Reflexive Modernization: Problematic, Hypotheses and Research Programme', *Theory, Culture and Society*, Vol. 20, No. 2, pp. 1 – 33.

Beck, Ulrich, Giddens, Anthony and Lash, Scott (1994a) 'Preface', in Beck, Ulrich, Giddens, Anthony and Lash, Scott (eds) *Reflexive Modernization: Politics, Tradition and Aesthetics in the Modern Social Order*, Cambridge: Polity Press.

Beck, Ulrich, Giddens, Anthony and Lash, Scott (1994b) *Reflexive Modernization: Politics, Tradition and Aesthetics in the Modern Social Order*, Cambridge: Polity Press.

Bloomfield, Brian P. and Vurdubakis Theo (1995) 'Disrupted Boundaries: New Reproductive Technologies and the Language of Anxiety and Expectation', *Social Studies of Science*, Vol. 25, pp. 533 - 551.

Bowring, Finn (2003) 'Therapeutic and Reproductive Cloning: A Critique', *Social Science and Medicine*, article in press.

British Medical Association (1999) 'BMA backs limited therapeutic cloning with strict safeguards', 24 June 1999. http://web.bma.org.uk/pressrel.nsf/a4a6effeb2d171b8802568590051feb8/49332ddf33b6da7b802568f500543109?OpenDocument [15/05/01].

Brown, Nik (2000) 'Organising/Disorganising the Breakthrough Motif: Dolly the Cloned Sheep Meets Astrid the Hybrid Pig', Online draft paper, http://www.york.ac.uk/org/satsu/OnLinePapers/NB/Breakthrough.htm [24/04/00].

Brown, Nik (2002) 'Transparency - The Very Idea', paper presented at Transparency in Public and Corporate Life, *Royal Society for the Arts*, 19 Sept 2002.

Brown, Nik and Michael, Mike (2002) 'From Authority to Authenticity: The Changing Governance of Biotechnology, *Health, Risk and Society*, Vol. 4, No. 3, pp. 259 - 272.

Butler, Judith (1990) *Gender Trouble: Feminism and the Subversion of Identity*, London: Routledge.

Butler, Judith (1993) *Bodies That Matter: On the Discursive Limits of "Sex"*, London: Routledge.

Clark, Andrew (2000) 'Blair Talks up Biotechs', *The Guardian*, 18 Nov http://www.guardianunlimited.co.uk/Archive/Archive/0,4273,4092801,00.html [20/11/00].

Clarke, Adele E. (2000) 'Maverick Reproductive Scientists and the Production of Contraceptives, 1915 - 2000+', in Saetnan, Ann Rudinow, Oudshoorn, Nelly and Kirejczyk, Marta (eds) *Bodies of Technology: Women's Involvement with Reproductive Medicine*, Columbus, Ohio: Ohio State University Press.

Clarke, Charlotte L. and Keady, John (2002) 'Getting Down to Brass Tacks: A Discussion of Data Collection with People with Dementia', in Wilkinson, Heather (ed.) *The Perspectives of People with Dementia: Research Methods and Motivations*, London: Jessica Kingsley Publishers.

Cohen, Philip and Carrington, Damian (2003) 'Baby Doctor Reveals Cloned Human Embryo', *New Scientist*, 9 April www.newscientist.com/news/news.jsp?id=ns99993610 [11/04/03].

Collins, H. M and Evans, Robert (2002) 'The Third Wave of Science Studies: Studies of Expertise and Experience', *Social Studies of Science*, Vol. 32, No. 2, April, pp. 235 - 296.

Collins, H. M. (1987) 'Certainty and the Public Understanding of Science: Science on Television', *Social Studies of Science*, Vol. 17, No. 4, pp. 689 - 714.

Crowe, Christine (1987) 'Women Want It: In Vitro Fertilization and Women's Motivations for Participation', in Patricia Spallone and Deborah Lynn Steinberg (eds) *Made to Order: The Myth of Reproductive and Genetic Progress*, Oxford: Pergamon Press.

Crowe, Christine (1990) 'Whose Mind Over Whose Matter? Women, In Vitro Fertilisation and The Development of Scientific Knowledge', in McNeil, Maureen et al. (eds.) (1990) *The New Reproductive Technologies*. Basingstoke: Macmillan.

Csordas, Thomas J. (1994) 'Introduction', in Csordas, Thomas J. (ed.) *Embodiment and Experience: The Existential Ground of Culture and Self*, Cambridge: Cambridge University Press.

Cunningham-Burley, Sarah and Kerr, Anne (1999) 'Defining the 'Social': Towards an Understanding of Scientific and Medical Discourses on the Social Aspects of the New Human Genetics', *Sociology of Health and Illness*, Vol. 21, No. 5, pp. 647-668.

Cussins, Charis (1996) 'Ontological Choreography: Agency through Objectification in Infertility Clinics', *Social Studies of Science*, Vol. 26, pp. 575-610.

Cussins, Charis (1998a) 'Ontological Choreography: Agency for Women Patients in an Infertility Clinic', in Berg, Marc and Mol, Annemarie (eds) *Differences in Medicine: Unravelling Practices, Techniques, and Bodies*, London: Duke University Press.

Cussins, Charis, M. (1998b) '"Quit Sniveling, Cryo-Baby. We'll Work Out Which One's Your Mama!"', in Robbie Davis-Floyd and Joseph Dumit (eds) *Cyborg Babies: From Techno-Sex to Techno-Tots*, London: Routledge.

Cussins, Charis, (1998c) 'Producing Reproduction: Techniques of Normalization and Naturalization in Infertility Clinics', in Franklin, Sarah and Ragoné, Helena (eds) (1998) *Reproducing Reproduction: Kinship, Power and Technological Innovations*, Philadelphia: University of Pennsylvania Press.

Department of Health (June 2000) *Stem Cell Research: Medical Progress with Responsibility*, London: Department of Health http://www.doh.gov.uk/cegc.

Douglas, Mary (1966) *Purity and Danger: An Analysis of Concepts of Pollution and Taboo*, London: Routledge.

Douglas, Mary (1970) *Natural Symbols: Explorations in Cosmology*, London: Barrie and Rockliff.

Douglas, Mary (1975) *Implicit Meanings: Essays in Anthropology*, London: Routledge.

Duden, Barbara (1999) 'The Fetus on the "Farther Shore": Towards a History of the Unborn', in Morgan, Lynn M. and Michaels, Meredith W. (eds) (1999) *Fetal Subjects, Feminist Positions*, Philadelphia: University of Pennsylvania Press.

Durant, John, Bauer, Martin W., and Gaskell, George (eds) (1998) *Biotechnology in the Public Sphere: A European Sourcebook*, London: Science Museum.

Edwards, Jeanette (2002) 'Taking 'Public Understanding' Seriously', *New Genetics and Society*, Vol. 21, No. 3, pp. 315-325.

Edwards, Rosalind (1993) 'An Education in Interviewing: Placing the Researcher and the Research', in Renzetti, Claire M. and Lee, Raymond M. (eds) *Researching Sensitive Topics*, London: Sage.

Eiensiedel, Edna et al. (2002) 'Brave New Sheep – The Clone Named Dolly', in Bauer, Martin W. and Gaskell, George (eds) *Biotechnology: The Making of a Global Controversy*, Cambridge: Cambridge University Press.

Ettorre, Elizabeth (2000) 'Reproductive Genetics, Gender and the Body: 'Please Doctor, May I Have a Normal Baby?" *Sociology*, Vol. 34, No. 3, pp. 403 - 420.

Ettorre, Elizabeth (2002) *Reproductive Genetics, Gender and the Body*, London: Routledge.

Farrar, Steve (1998a) 'Scientists to Grow a Human Heart', *The Sunday Times*, Oct 11.

Farrar, Steve (1998b) 'Lab-grown Hearts to Solve Donor Crisis', *The Sunday Times*, Oct 11.

Featherstone, Mike and Wernick, Andrew (eds) (1995) *Images of Aging: Cultural Representations of Later Life*, London: Routledge.

Foucault, Michel (1966) *The Order of Things: An Archaeology of the Human Sciences* (trans. 1970), Bristol: Tavistock Publications.

Foucault, Michel (1979) *The History of Sexuality Vol. 1: An Introduction* (trans. Robert Hurley), Harmondsworth, Middlesex: Penguin.

Franklin, Sarah (1993) 'Postmodern Procreation: Representing Reproductive Practice', *Science as Culture*, Vol. 3, Pt. 4, No. 17, pp. 522 - 561.

Franklin, Sarah (1997) *Embodied Progress: A Cultural Account of Assisted Conception*, London: Routledge.

Franklin, Sarah (1998) 'Making Miracles: Scientific Progress and the Facts of Life', in Ragoné, Helena and Franklin, Sarah (eds) (1998) *Reproducing Reproduction: Kinship, Power and Technological Innovation*, Philadelphia: University of Pennsylvania Press.

Franklin, Sarah (1999) 'Making Representations: The Parliamentary Debate on the Human Fertilisation and Embryology Act', in Edwards, J. et al. (eds.) (1999) *Technologies of Procreation: Kinship in the Age of Assisted Conception*, (2nd Ed.) London: Routledge.

Franklin, Sarah (2001a) 'Sheepwatching', *Anthropology Today*, Vol. 17, No. 3 (June 2001).

Franklin, Sarah (2001b) 'Biologization Revisited: Kinship Theory in the Context of the New Biologies', in Franklin, Sarah and McKinnon, Susan (eds) *Relative Values: Reconfiguring Kinship Studies*, Durham, NC: Duke University Press.

Franklin, Sarah (2001c) 'Culturing Biology: Cell Lines for the Second Millennium', *Health*, Vol. 5, No. 3, pp. 335 - 354.

Franklin, Sarah (2000d) *Review Essay: What We Know And What We Don't About Cloning and Society*, (draft) published by the Dept. of Lancaster, Lancaster University at: http://www.comp.lancs.ac.uk/sociology/soc020sf.html.

Franklin, Sarah, Anthony Rutherford & Peter Braunde (2001) 'Project Outline', in ESRC funded project: Innovative Health Technologies Initiative, http://www.comp.lancs.ac.uk/sociology/IHT/Mainpage.htm.

Franklin, Sarah, Lury, Celia & Stacey, Jackie (eds) (2000) *Global Nature, Global Culture*, London: Sage.

Franklin, Sarah and Roberts, Celia (2001) *The Social Life of the Embryo*, Department of Sociology, Lancaster University, http://www.comp.lancs.ac.uk/sociology/iht/eofcpaper.htm [11/06/02].

Furedi, Frank (1997) *Culture of Fear: Risk Taking and the Morality of Low Expectation*, London: Cassell.

Garfield, Eugene and Holton, Gerald (1984) 'Twins. Part 2. The Twin Study Method in Behavioural and Clinical Research', *Essays of an Information Scientist*, Vol. 7, No. 49, December, pp 397 - 404.

Gaskell, George and Bauer, Martin (eds) (2001) *Biotechnology 1996 - 2000: The Years of Controversy*, London: Science Museum.

Giddens, Anthony (1990) *The Consequences of Modernity*, Cambridge: Polity Press.

Giddens, Anthony (1991) *Modernity and Self-Identity: Self and Society in the Late Modern Age*, Cambridge: Polity Press.

Gieryn, Thomas F. (1983) 'Boundary-Work and the Demarcation of Science from Non-Science: Strains and Interests in Professional Ideologies of Scientists', *American Sociological Review*, Vol. 48, Issue 6 (December), pp 781 - 795.

Gieryn, Thomas F. (1995) 'Boundaries of Science', in Jasanoff, Sheila, Markle, Gerald E., Petersen, James C. and Pinch, Trevor (eds) *Handbook of Science and Technology Studies*, London: Sage.

Gilbert, Nigel G. and Mulkay, Michael (1984) *Opening Pandora's Box: A Sociological Analysis of Scientists' Discourse*, London: Cambridge University Press.

Glasner, Peter (2002) 'Beyond the Genome: Reconstituting the New Genetics', *New Genetics and Society*, Vol. 21, No. 3, pp. 267 - 277.

Goslinga-Roy, Gillian M. (2000) 'Body Boundaries, Fiction of the Female Self: An Ethnographic Perspective on Power, Feminism, and the Reproductive Technologies', *Feminist Studies*, Vol. 26, No. 1, (Spring 2000).

Graham, Elaine L. (2002) *Representations of the Post/Human: Monsters, Aliens and Others in Popular Culture*, Manchester: Manchester University Press.

Hall, Stuart (1980) 'Encoding/Decoding', in Hall, Stuart, Hobson, Dorothy, Lowe, Andrew and Willis, Paul (eds) *Culture, Media, Language: Working Papers in Cultural Studies, 1972-79*, London: Hutchinson.

Hansard, House of Commons debates, 17 Nov 2000. http://www.parliament.the-stationary-office.co.uk/pa/cm199900/cmhansrd/cm001117/debindx-x.htm.

Hansard, House of Commons debates, 19 Dec 2000. http://www.parliament.the-stationery-office.co.uk/pa/cm200001/cmhansrd/vo001219/debtext/01219-07.htm#01219-07_head0.

Hansard, House of Lords debates, 22 Jan 2001. http://www.parliament.the-stationary-office.co.uk/pa/ld199900/ldhansrd/pdrn/lds01/text/10122w01.htm.

Hansard, House of Lords debates, 3 Sept 1998. http://www.parliament.the-stationery-office.co.uk/pa/ld199697/ldhansrd/pdvn/lds98/text/80903w16.htm.

Haraway, Donna (1991) *Simians, Cyborgs and Women: The Reinvention of Nature*, London: Free Association Press.

Haraway, Donna (1992) 'The Promises of Monsters: A Regenerative Politics for Inappropriate/d others', in Lawrence Grossberg, Cary Nelson and Paula Treichler (eds) *Cultural Studies*, New York: Routledge.

Haraway, Donna (1997a) 'Mice Into Wormholes: A Comment on the Nature of No Nature', in Downy, Gary Lee and Dumit, Joseph (eds) *Cyborgs and Citadels: Anthropological Interventions in Emerging Sciences and Technologies*, Santa Fe: School of American Research Press.

Haraway, Donna (1997b) *Modest_Witness@Second_MilleniumFemaleMac©_Meets_OncoMouse™: Feminism and Technoscience*, London: Routledge.

Hareven, Tamara, K. (1995) 'Changing Images of Aging and the Social Construction of the Life Course', in Mike Featherstone and Andrew Wernick (eds) *Images of Aging: Cultural Representations of Later Life*, London: Routledge.

Hargreaves, Ian, Lewis, Justin and Speers, Tammy (2003) *Towards a Better Map: Science, the Public and the Media*, Swindon: Economic and Social Research Council.

Harris, John (1998) *Clones, Genes, and Immortality: Ethics and the Genetic Revolution*, Oxford: Oxford University Press.

Henderson, Mark (2000) 'Britain's Biotech Talent May Flee 'Hostile' Climate', *The Times*, Nov 15 http://www.thetimes.co.uk/article/0,,2-35902,00.html [17/04/01].

Holland, Suzanne, Lebacqz, Karen and Zoloth, Laurie (eds) (2001) *The Human Embryonic and Stem Cell Debate: Science, Ethics and Public Policy*, London: MIT Press.

House of Lords Select Committee on Science and Technology (2000) *Science and Society*, Third Report, 23 February 2000. http://www.publications.parliament.uk/pa/ld199900/ldselect/ldsctech/38/3801.htm.

House of Lords Select Committee on Stem Cell Research (2002) *Stem Cell Research: Report from the Select Committee*, London: The Stationary Office Ltd.

Human Fertilisation and Embryology Code of Practice, Fifth Edition, April 2001. http://www.hfea.gov.uk/code2001/cop2001/pdf.

Human Genetics Advisory Commission and Human Fertilisation and Embryology Authority (January 1998) *Cloning Issues in Reproduction, Science and Medicine*, http://www.dti.gov.uk/hgac/papers/paperc1.htm.

Irwin, Alan (1995) *Citizen Science: A Study of People, Expertise and Sustainable Development*, London: Routledge.

Irwin, Alan (2001) 'Constructing the Scientific Citizen: Science and Democracy in the Biosciences', *Public Understanding of Science*, Vol 10, pp. 1-18.

Irwin, Alan and Wynne, Brian (eds) (1996a) *Misunderstanding Science? The Public Reconstruction of Science and Technology*, Cambridge: Cambridge University Press.

Irwin, Alan and Wynne, Brian (1996b) 'Introduction', in Irwin, Alan and Wynne, Brian (eds) *Misunderstanding Science? The Public Reconstruction of Science and Technology*, Cambridge: Cambridge University Press.

Irwin, Alan and Wynne, Brian (1996c) 'Conclusions', in Irwin, Alan and Wynne, Brian (eds) *Misunderstanding Science? The Public Reconstruction of Science and Technology*, Cambridge: Cambridge University Press.

Jasanoff, Sheila (1987) 'Contested Boundaries in Policy-Relevant Science', *Social Studies of Science*, Vol. 17, pp. 195 - 230.

Jasanoff, Sheila (2002) 'New Modernities: Reimagining Science, Technology and Development', *Environmental Values*, Vol. 11, pp. 253-276.

Keller, Evelyn Fox (1995) *Refiguring Life: Metaphors of Twentieth-Century Biology*, New York: Columbia University Press.

Kember, Sarah (2002) 'Reinventing Cyberfeminism: Cyberfeminism and the New Biology', *Economy and Society*, Vol 31. No. 4, pp. ???

Kerr, Anne, Cunningham-Burley, Sarah, Amos, Amanda (1997) 'The New Genetics: Professionals' Discursive Boundaries', *Sociological Review*, Vol 45, No. 2, pp. 279-303.

Kerr, Anne, Cunningham-Burley, Sarah, Amos, Amanda (1998a) 'Drawing the Line: An Analysis of Lay People's Discussions About the New Genetics', *Public Understanding of Science*, Vol. 7, No. 2, pp. 113 - 133.

Kerr, Anne, Cunningham-Burley, Sarah, Amos, Amanda (1998b) 'The New Genetics and Health: Mobilizing Lay Expertise', *Public Understanding of Science*, Vol. 7, No. 1, pp. 41 - 60.

Kerr, Anne and Cunningham-Burley, Sarah (1999) 'On Ambivalence and Risk: Reflexive Modernity and the New Human Genetics', *Sociology*, Vol. 34, No. 2, pp. 283-304.

Kirejczyk, Marta (1993) 'Shifting the Burden onto Women: The Gender Character of *In Vitro* Fertilisation', *Science as Culture*, Vol. 3, Pt. 4, No. 17, pp. 507-521.

Kirejczyk, Marta (1995) *Gender and the Social Entrenchment of IVF in the Netherlands*, Paper for the International Workshop on the Mutual Shaping of Gender and Technology, Enschede, October 6-8, 1995.

Kirejczyk, Marta (1999) 'Parliamentary Cultures and Human Embryos: The Dutch and British Debates Compared', *Social Studies of Science*, Vol. 29, No. 6 (December 1999), pp. 889-912.

Kitzinger, Jenny (1996) 'Focus Groups With Users and Providers of Health Care', in Pope, Catherine and Mays, Nicholas (eds) *An Introduction to Qualitative Methods for Health Professionals*, London: BMJ Publishing Group.

Kitzinger, Jenny and Barbour, Rosaline S. (1999) 'Introduction: The Challenge and Promise of Focus Groups', in Barbour, Rosaline S. and Kitzinger, Jenny (eds) *Developing Focus Group Research: Politics, Theory and Practice*, London: Sage.

Koch, Lene (1992) 'The Fairy Tale As Model For Women's Experience Of In Vitro Fertilization', in Helen Bequaert Holmes (ed) *Issues In Reproductive Technology I: An Anthology*, London: Garland Publishing.

Kolata, Gina (1997) *Clone: The Road to Dolly and the Path Ahead*, London: Penguin Press.

Kristeva, Julia (1982) *Powers of Horror: An Essay on Abjection*, New York: Columbian University Press.

Lash, Scott (1994) 'Reflexivity and its Doubles: Structure, Aesthetics, Community', in Beck, Ulrich, Giddens, Anthony and Lash, Scott (eds) *Reflexive Modernization: Politics, Tradition and Aesthetics in the Modern Social Order*, Cambridge: Polity Press.

Lash, Scott (2000) 'Risk Culture', in Adam, Barbara, Beck, Ulrich and Van Loon, Joost (eds) *The Risk Society and Beyond: Critical Issues for Social Theory*, London: Sage.

Lash, Scott (2003) 'Reflexivity as Non-Linearity', *Theory, Culture and Society*, Vol. 20, No. 2, pp. 49 - 57.

Latour, Bruno (1988) 'How to Write 'The Prince' for Machines as well as for Machinations', in Elliott, Brian (ed.) *Technology and Social Change*, Edinburgh: Edinburgh University Press. http://www.ensmp.fr/ ~latour/articles/article/036.html.

Latour, Bruno (2003) 'Is *Re*-Modernization Occurring - And If So, How to Prove It? A Commentary on Ulrich Beck', *Theory, Culture and Society*, Vol. 20, No. 2, pp. 35 - 48.

Lee, Raymond, M. (1993) *Doing Research on Sensitive Topics*, London: Sage.

Lock, Margaret (2002) *Twice Dead: Organ Transplants and the Reinvention of Death*, London: University of California Press.

Löfstedt, Ragnar E. and Frewer, Lynn (1998) 'Introduction', in Löfstedt, Ragnar E. and Frewer, Lynn (eds) *The Earthscan Reader in Risk and Modern Society*, London: Earthscan.

Lundin, Susanne (2002) 'Creating Identity with Biotechnology: The Xenotransplanted Body as the Norm', *Public Understanding of Science*, Vol. 11, pp. 333 - 345.

Longhurst, Robyn (2001) *Bodies: Exploring Fluid Boundaries*, London: Routledge.

Lupton, Deborah (1999) *Risk*, London: Routledge.

MacCormack, Carol (1980) 'Nature, Culture and Gender: A Critique', in MacCormack, Carol and Strathern, Marilyn (eds) *Nature, Culture and Gender*, Cambridge: Cambridge University Press.

MacKenzie, Donald (1998) 'The Certainty Trough', in Williams, Robin, Faulkner, Wendy and Fleck, James (eds) *Exploring Expertise: Issues and Perspectives*, London: MacMillan.

Macnaughten, Phil and Urry, John (1998) *Contested Natures*, London: Sage.

Macnaughten, Phil and Urry, John (2000) 'Bodies of Nature: Introduction', *Body and Society*, Vol. 6, No., 3-4, pp. 1-11.

Martin, Emily (1996) 'The Egg and the Sperm: How Science has Constructws a Romance Based on Stereotypical Male-Female Roles', in Keller, Evelyn Fox and Longino, Helen (eds) (1996) *Feminism and Science*, Oxford: Oxford University Press.

May, Tim (1993) *Social Research: Issues, Methods and Process*, Buckingham: Open University Press.

McGee, Glenn (ed.) (1998) *The Human Cloning Debate*, Berkeley, California: Berkeley Hills Books.

McNeil, Maureen (1993) 'New Reproductive Technologies: Dreams and Broken Promises', *Science as Culture*, Vol. 3, No. 17, pp. 483 - 506.

McNeil, Maureen (1998) 'Gender, Expertise and Feminism', in Williams, Robin, Faulkner, Wendy and Fleck, James (eds) *Exploring Expertise: Issues and Perspectives*, London: MacMillan Press.

McNeil, Maureen and Franklin, Sarah (1991) 'Science and Technology: Questions for Cultural Studies and Feminism', in Franklin, Sarah, Lury, Celia and Stacey, Jackie (eds) *Off-Centre: Feminism and Cultural Studies*, New York: Harper Collins.

Meek, James (2001) 'The Brain Gain', *The Guardian*, Tuesday 14 August 2001.

Meek, James (2002) 'Cloning Team Looks to Human Embryos', *The Guardian*, October 14th, 2002 www.guardian.co.uk/genes/article/0,2763,811272,00.html [14/10/02].

Michael, Mike (1996a) *Constructing Identities: The Social, the Nonhuman and Change*, London: Sage.

Michael, Mike (1996b) 'Ignoring Science: Discourses of Ignorance in the Public Understanding of Science', in Irwin, Alan and Wynne, Brian (eds) *Misunderstanding Science? The Public Reconstruction of Science and Technology*, Cambridge: Cambridge University Press.

Michael, Mike (1998) 'Between Citizen and Consumer: Multiplying the Meanings of the "Public Understanding of Science"', *Public Understanding of Science*, Vol. 7, pp. 313 - 327.

Michael, Mike (2000) *Reconnecting Culture, Technology and Nature: From Society to Heterogeneity*, London: Routledge.

Michael, Mike and Carter, Simon (2001) 'The Facts About Fictions and Vice Versa: Public Understanding of Human Genetics', *Science as Culture*, vol. 10, No. 1, pp. 5 - 32.

Morgan, David L. and Krueger, Richard A. (1993) 'When to Use Focus Groups and Why', in Morgan, David L. (ed.) *Successful Focus Groups: Advancing the State of the Art*, Newbury Park, California: Sage.

Morgan, Lynn M. and Michaels, Meredith W. (eds) (1999) *Fetal Subjects, Feminist Positions*, Philadelphia: University of Pennsylvania Press.

Mulkay, Michael (1993) 'Rhetorics of Hope and Fear in the Great Embryo Debate', *Social Studies of Science*, Vol. 23, pp. 721 - 742.

Mulkay, Michael (1994) 'The Triumph of the Pre-Embryo: Interpretations of the Human Embryo in Parliamentary Debate over Embryo Research', *Social Studies of Science*, Vol. 24, pp. 611-639.

Mulkay, Michael (1997) *The Embryo Research Debate: Science and the Politics of Reproduction*, Cambridge: Cambridge University Press.

Mulkay, Michael, Potter, Jonathan, and Yearley, Steven (1983) 'Why an Analysis of Scientific Discourse is Needed', in Knorr-Cetina, Karin and Mulkay, Michael (eds) *Science Observed: Perspectives on the Social Study of Science*, London: Sage.

Myers, Greg (1990) *Writing Biology: Texts in the Social Construction of Scientific Knowledge*, Wisconsin: University of Wisconsin Press.

National Research Council/Institute of Medicine (2002) *Stem Cells and the Future of Regenerative Medicine*, Washington D.C: National Academy Press.

Nerlich, Brigitte and Clarke, David D. (2003) 'Anatomy of a Media Event: How Arguments Clashed in the 2001 Human Cloning Debate', *New Genetics and Society*, Vol. 22, No. 1, pp. 43 – 59.

Nettleton, Sarah (1995) *The Sociology of Health and Illness*, Cambridge: Polity Press.

Nisbet, Matthew C., Brossard, Dominique, and Kroepsch, Adrianne (2003) 'Framing Science: The Stem Cell Controversy in an Age of Press/Politics', *Press/Politics*, Vol. 8, No. 2, pp. 36 – 70.

Novas, Carlos and Rose, Nikolas (2000) 'Genetic Risk and the Birth of the Somatic Individual', *Economy and Society*, Vol. 29, No. 4, pp. 485 – 513.

Nussbaum, Martha C. and Sunstein, Cass R. (eds) (1999) *Clones and Clones: Facts and Fantasies About Human Cloning*, London: W. W. Norton & Company.

Paterson, Kevin & Hughes, Bill (2000) 'Disabled Bodies', in Hancock, Philip *et al.* (2000) *The Body, Culture and Society: An Introduction*, Buckingham: Open University Press.

Petersen, Alan (2001) 'Biofantasies: Genetics and Medicine in the Print News Media', *Social Science and Medicine*, Vo., 52, pp. 1255 – 1268.

Petersen, Alan (2002) 'Replicating Our Bodies, Losing Our Selves: News Media Portrayals of Human Cloning in the Wake of Dolly', *Body and Society*, Vol. 8, No. 4, pp. 71 – 90.

Pfeffer, Naomi (1987) 'Artificial Insemination, In-vitro Fertilization and the Stigma of Infertility', in Stanworth, Michelle (1987) *Reproductive Technologies: Gender, Motherhood and Medicine*, Cambridge: Polity Press.

Pidgeon, Nick (1996) 'Grounded Theory: Theoretical Background', in Richardson (ed.) *Handbook of Qualitative Methods for Psychology and the Social Sciences*, Leicester, British Psychology Society.

Pilcher, Jane (1995) *Age and Generation in Modern Britain*, Oxford: Oxford University Press.

Pinch, Trevor J. and Bijker, Wiebe E. (1984) 'The Social Construction of Facts and Artefacts: or How the Sociology of Science and the Sociology of Technology might Benefit Each Other', *Social Studies of Science*, Vol. 14, pp. 399-441.

Ploeg, Irma van der (1995) 'Reproductive Technology's Hybrids: 'Couples', 'Fetuses' and the Dissolution of the Individual Female Body', unpublished paper presented at the *International Workshop on the Mutual Shaping of Gender and Technology*, University of Twente, October 6-8, 1995.
Public Understanding of Science (1992) 'Chernobyl Special Issue', Vol. 1, No. 3, pp. 241-344.

Price, Frances (1999) 'Beyond Expectation: Clinical Practices and Clinical Concerns', in Edwards, J., Franklin, S., Hirsch, E., Price, F., and Strathern, M., (eds) (2nd Ed.) *Technologies of Procreation: Kinship in the Age of Assisted Conception*, London: Routledge.

Puwar, N (1997) Reflections on Interviewing Women MPs, *Sociological Research Online*, Vol. 2, No. 1 http://socresonline.org.uk/socresonline/2/1/4.html.

Radford, Tim (1998a) 'The Human Cells That Will Revolutionise Medicine', *The Guardian*, Nov 6.

Radford, Tim (1998b) 'How the Human Machine Gave Up Another of its Secrets', *The Guardian*, Nov 6.

Radford, Tim (1998c) 'Cloning To Be Used To Fight Disease', *The Guardian*, Dec 9.

Radford, Tim (1999) 'Mice Given Extra Gene Become Smarter', *The Guardian*, Sept 2.

Rapp, Rayna (1999) *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*, London: Routledge.

RBM Online (2003) Vol. 6, No. 4, June.

Reinel, Birgit (1999) 'Reflections on Cultural Studies of Technoscience', *European Journal of Cultural Studies*, Vol. 2, No. 2, pp. 163-189.

Rogers, Lois and Farrar, Steve (1999) ' 'Immortal' Genes Founds by Science', *The Sunday Times*, July 4.

Rose, Hilary (1994) *Love, Power and Knowledge: Towards a Feminist Transformation of the Sciences*, Cambridge: Polity Press.

Rose, Nikolas (2001) 'The Politics of Life Itself', *Theory, Culture and Society*, Vol. 18, No. 6, pp. 1-30.

Royal Society, Science in Society Programme, http://www.royalsoc.ac.uk/scienceinsociety/data/about/index.html.

Sadri, Ahmad (1994) 'Doppelganger: Twins' Disruption of the Assumptions of Constancy and Uniqueness of Self in Everyday Life', *Symbolic Interaction*, Vol. 12, No. 2, pp. 203 - 223.

Sætnan, Ann Rudinow (1996) 'Speaking of Gender ... : Intertwinings of a Medical Technology Policy Debate and Everyday Life', in Lie, Merete and Sørensen, Knut H. (eds) *Making Technology Our Own? Domesticating Technology into Everyday Life*, Oslo: Scandinavian University Press.

Salter, Brian (2003) 'Patients and Doctors: Reformulating the UK Health Policy Community', *Social Science and Medicine*, Vol. 57, No. 5, pp. 927 - 936.

Schulman, Norma (1993) Conditions of their Own Making: An Intellectual History of the Centre for Contemporary Cultural Studies at the University of Birmingham, *Canadian Journal of Communications*, Vol. 18, No. 1 http://www.wlu.ca/ ~wwwpress/jrls/cjc/BackIssues/18.1/schulman.html.

Sexton, Sarah (1999) 'If Cloning is the Answer, What was the Question?: Power and Decision-Making in the Geneticisation of Health', in *The Corner House*, Briefing 16, 1999. http://cornerhouse.icaap.org/briefings/16.html [06/04/01].

Slovic, Paul (1998) 'Perceived Risk, Trust and Democracy', in Löfstedt, Ragnar E. and Frewer, Lynn (eds) *The Earthscan Reader in Risk and Modern Society*, London: Earthscan.

Smart, Andrew (2003) 'Reporting the Dawn of the Post-Genomic Era: Who Wants to Live Forever?', *Sociology of Health and Illness*, Vol., 25, No., 1, pp. 24 - 49.

Smith, Austin (2001) 'Response to a Questionnaire, Summer 2001', Temporary Committee on Human Genetics and Other New Technologies of Modern Medicine, *European Parliament* http://www.europarl.eu.int/comparl/tempcom/genetics/intro_en.htm.

Soper, Kate (1995) *What is Nature?: Culture, Politics and the non-Human*, Oxford: Blackwell.

Spallone, Patricia (1986) 'The Warnock Report: The Politics of Reproductive Technology', *Women's Studies International Forum*, Vol. 9, No. 5, pp. 543-550.

Spallone, Patricia (1989) *Beyond Conception: The New Politics of Reproduction*, London: MacMillan Education.

Stacey, Jackie (1997) *Teratologies: A Cultural Study of Cancer*, London: Routledge.

Strathern, Marilyn (1992a) *Reproducing the Future: Anthopology, Kinship and the New Reproductive Technologies*, Manchester: Manchester University Press.

Strathern, Marilyn (1992b) *After Nature: English Kinship in the Late Twentieth Century*, Cambridge: Cambridge University Press.

Szerszynski, Bronislaw (1999) 'Risk and Trust: The Performative Dimension', *Environmental Values*, Vol. 8, pp. 239 - 252.

Take Two: Identical Twins in Focus, Wellcome Trust Science and Art Exhibitions, http://www.wellcome.ac.uk/en/old/taketwo/MISexhTWOtwnBGD1.html [13/03/02].

The Public Consultation on Developments in the Biosciences (1999) MORI/OST, London http://www.dti.gov.uk/ost/ostbusiness/puset/bio_consult.pdf.

Thomas, Jeff (1997) 'Informed Ambivalence: Changing Attitudes to the Public Understanding of Science', in Levinsons, Ralph and Thomas, Jeff (eds) *Science Today: Problem or Crisis?*, London: Routledge.

Thompson, J. A. et al. (1998) 'Embryonic Stem Cell Lines Derived From Human Blastocysts', *Science*, 282, pp. 1145 - 1147.

Tonkiss, Fran (1998) 'Analysing Discourse', in Seale, Clive (ed.) *Researching Society and Culture*, London: Sage.

Tulle-Winton, Emmanuelle (2000) 'Old Bodies', in Hancock, Philip *et al.*, (eds) *The Body, Culture and Society: An Introduction*, Buckingham, Open University Press.

Turner, Bryan S. (1995) 'Aging and Identity: Some Reflections on the Somatization of the Self', in Featherstone, Mike and Wernick, Andrew (eds) (1995) *Images of Aging: Cultural Representations of Later Life*, London: Routledge.

Turner, Bryan S. (1996) *The Body and Society* (2nd Edition). London: Sage.

Turney, Jon (198) *Frankenstein's Footsteps: Science, Genetics and Popular Culture*, London: Yale University Press.

Van Dijck, José (1995) 'Engendering Genetics', *International Workshop on the Mutual Shaping of Gender and Technology*, Enschede, Netherlands, 6-8 Oct.

Van Dijck, José (1998) *Imagenation: Popular Images of Genetics*, London: MacMillan Press.

Van Dijck, José (1999) 'Cloning Humans, Cloning Literature: Genetics and the Imagination Deficit', *New Genetics and Society*, Vol. 18, No. 1, pp 9 – 22.

Van Dyck, José (1995) *Manufacturing Babies and Public Consent: Debating the New Reproductive Technologies*. Basingstoke: MacMillan.

Van Loon, Joost (2002) *Risk and Technological Culture: Towards a Sociology of Virulence*, London: Routledge.

Warnock, Mary (1985) *A Question of Life: The Warnock Report on Human Fertilization and Embryology*, Oxford: Blackwell.

Wellcome Trust (1998) *Public Perspectives on Human Cloning: A Social Research Study*, London: The Wellcome Trust.

Wilkinson, Heather (ed.) (2002) *The Perspectives of People with Dementia: Research Methods and Motivations*, London: Jessica Kingsley Publishers.

Wilmut, Ian, Campbell, Keith and Tudge, Colin (2000) *The Second Creatoin: The Age of Biological Control by the Scientists Who Created Dolly*, London: Headline.

Williams, Clare, Kitzinger, Jenny and Henderson, Lesley (2003) 'Envisaging the Embryo in Stem Cell Research: Rhetorical Strategies and Media Reporting of the Ethical Debates', *Sociology of Health and Illness*, Nov, 2003 (forthcoming).

Wynne, Brian (1988) 'Unruly Technology: Practical Rules, Impractical Discourses and Public Understanding', *Social Studies of Science*, Vol. 18, pp. 147 – 167.

Wynne, Brian (1992) 'Misunderstood Misunderstanding: Social Identities and Public Uptake of Science', *Public Understanding of Science*, Vol. 1, No. 3, pp. 281-304.

Wynne, Brian (1995) 'Public Understanding of Science', in Jasanoff, Sheila et al. (eds) *Handbook of Science and Technology Studies*, Thousand Oaks, CA: Sage.

Wynne, Brian (1996) 'May The Sheep Safely Graze? A Reflexive View of the Expert-Lay Knowledge Divide', in Lash, Scott, Szerszynski, Bronislaw and Wynne, Brian (eds) *Risk, Environment and Modernity: Towards A New Ecology*, London: Sage.

Wynne, Brian (2002) 'Risk and Environment as Legitimatory Discourses of Technology: Reflexivity Inside Out?', *Current Sociology*, Vol. 50, No. 3, pp. 459-477.

Yearley, Steven (2000) 'What Does Science Mean in the "Public Understanding of Science"?', in Meindolf, Dierkes and Von Grote, Claudia (eds) *Between Understanding and Trust: The Public, Science and Technology*, Amsterdam: Harwood Academic Publishers.

APPENDIX I

The Politics of Cloning: Mapping the rhetorical convergence of embryos and stem cells in Parliamentary debates[i]

Abstract

In April 2001 the 1990 Human Fertilisation and Embryology Act (HFE Act) was amended to allow stem cell research (SCR) to use human embryos. By identifying what Mulkay calls 'discursive regularities' (1993: 723), this paper examines the rhetorical strategies of and manoeuvrings over the meanings of stem cells, cloning and embryos within the Parliamentary context. I focus upon the 'return to the embryo question' and the significance of this for the stem cell debates in terms of form and content. This feeds into an analysis of the ways in which two specific groups are discursively invoked and constructed - those with diseases and disabilities who have been identified as likely to benefit from stem cell therapies, and couples undergoing fertility treatment who are needed to donate spare embryos. In doing so, I draw upon similar analyses of the earlier embryo debates - those of Mulkay, Franklin, Kirejczyk and Spallone – leading up to the establishment of the 1990 HFE Act. In conjunction with these analyses, I am able to identify parallels between the rhetorical devices mobilised and the legislative outcomes.

Introduction

Whilst human embryonic SCR has been carried out since the mid-nineteen nineties, it was not until after the birth of Dolly the sheep that the Government formerly addressed policy issues surrounding related developments. Between 1997, the year Dolly was announced, and early 2001, the Government commissioned a consultation paper by the Human Fertilisation and Embryology Authority (HFEA) and the Human Genetics Advisory Commission (HGAC), and established an expert advisory committee headed by the Chief Medical Officer, Professor Liam

Donaldson. The outcome of these papers was a proposal to amend the existing 1990 HFE Act, that culminated in a series of parliamentary debates to decide upon the future of SCR. The proposed amendment would add a further three categories for embryo research to the existing five.[ii] The amendment was passed in a non-party vote in the House of Commons with 366 ayes and 174 noes, then passed to the House of Lords who divided with 212 ayes, and 92 noes.

As in the debates that led to the establishment of the 1990 HFE Act, the stem cell debates demonstrated that there is still no consensus as to the moral status of the embryo. Indeed, it appears that recent developments in cloning and genetic technologies have further problematised questions of life as they relate to embryo research. The significance of Dolly was not the ability of scientists to clone *per se*, but the demonstration that cells taken from an adult mammal could be 're-programmed' – a process called de-differentiation – to produce a genetically identical copy of the original.[iii] If adult cells can be de-differentiated, then this offers new avenues for scientific research to understand not only how cells become specialised, but also how to control that process. Consequently, we have seen speculation regarding a number of applications, including reproductive cloning, stem cell therapies and xenotransplantation.

This paper examines some of the rhetorical resources and strategies used during the stem cell debates vis-à-vis analyses of the pre-1990 embryo debates. I will draw upon my analyses of three Hansard transcripts of stem cell debates: two from the House of Commons (17 November and 19 December 2000) and one from the House of Lords (22 January 2001). By focussing upon what Mulkay calls 'discursive regularities' (1993: 723), I map the contours of the debates that dominated discussions of stem cell cloning in Parliament. I have not focussed upon the specific accounts of individual speakers, nor provided a comprehensive comparison of the broadly pro and anti-research arguments.[iv] Instead, this paper identifies discursive regularities of the stem cell debates comprising typical assertions that reflected the recurrent themes, ideas, assumptions and discourses that were mobilised during Parliamentary discussions.

Discussion of the embryo debates during the 1980s is enabled through a selective comparison to analyses conducted by Michael Mulkay (1997), Sarah Franklin (1997, 1999), Marta Kirejczyk (1993, 1995, 1999) and Patricia Spallone (1986, 1989). In comparing the 'recurrent interpretative practices employed' (Gilbert and Mulkay, 1984: 14) by parliamentarians during the 1990 HFE Act debates with those of the stem cell debates, I will identify the discursive points of convergence. The form and content of SCR and cloning related developments are shown to be constructed according to pre-existing sociocultural discourses that reveal the 'interrelated set of background assumptions' of the speakers (Mulkay, 1993: 723).

Managing the debate: Scene setting and lobbying prior to the Parliamentary debates

The announcement of Dolly the sheep in February 1997 opened the floodgates for debates on the implications of the growing biotechnology industry for humans and society. Religious leaders, politicians, patient groups, scientists and non-affiliated individuals, have voiced their particular perspectives on the subject. In response to the escalating public debates, in 1997 the Human Genetics Advisory Commission (HGAC) and the Human Fertilisation and Embryology Authority (HFEA) held a joint consultation exercise resulting in a published report, *Cloning Issues in Reproduction, Science and Medicine* (January 1998). From this very early stage in the public debates there emerged signs of the rhetorical severing of therapeutic cloning from reproductive cloning. Whilst it was recommended that reproductive cloning should remain illegal, and required primary legislation to explicitly ban it, therapeutic cloning was deemed to hold the promise of medical benefits. This distinction lay in the intention and purpose of the research rather than the cloning technique per se. It was considered that the uses of reproductive cloning would be unethical, unsafe and inefficient as a means for human reproduction. Therapeutic cloning, however, was not considered to produce the same ethical problems as cloning whole human beings. That therapeutic cloning is the use of cloning techniques for potentially curing a

multitude of diseases was an important aspect of the argument for separating the ethical issues of reproductive cloning from this 'benevolent technique'. Furthermore, in an attempt to avoid the stigma of the word 'cloning', the HFEA/HGAC report changed the terminology from 'therapeutic *cloning*' to 'therapeutic uses of *cell nuclear replacement*' (my emphasis).

The HGAC/HFEA report advised government to extend the HFEA regulations to include two further purposes for research: 'developing methods of therapy for mitochondrial diseases and developing methods of therapy for diseased or damaged tissue or organs' (1998: 9.3). The government responded to this report in June 1999 by establishing an expert advisory group, the Donaldson committee, to consider the proposed changes to the HFE Act that would allow SCR with a view to developing therapeutic uses of cloning techniques.

Between 1999 and the Parliamentary debates in late 2000, numerous science-based organisations published reports and press releases in the UK explicitly outlining their position on the matter of cloning and its applications and implications for humans. These include the Nuffield Council on Bioethics, Royal Society, Medical Research Council (MRC), British Medical Association (BMA) and the Association of Medical Research Charities (AMRC). The report of Donaldson Committee, *Stem Cell Research: Medical Progress with Responsibility* (Department of Health, June 2000), opened by focussing upon the distinction between reproductive and therapeutic cloning. Stem cell research using cloning techniques was supported for therapeutic purposes, organisations such as the BMA stated that they remained 'resolutely opposed to the cloning of whole humans' (BMA press release, 24 June 1999). Whilst identifying various ethical problems caused by the prospect of cloning humans, such as the devaluation and commodification of life, therapeutic cloning was constructed as presenting no new ethical dilemmas. These arguments were based upon the grounds that the aims and objectives of the research and its potential applications differ: one aims to provide treatment for a variety of diseases and conditions whilst the other aims to produce a cloned human. This position, as advocated by science-related

organisations, was endorsed by the Donaldson Committee's report which clearly separated reproductive and therapeutic cloning mobilising arguments outlined by the pro-SCR lobby.

Initial public responses to the development of cell nuclear replacement, the technique used to clone Dolly, were captured in the Wellcome Trust's study *Public Perspectives on Human Cloning* in 1998. Issues covered by the focus group participants addressed a broad range of social, moral and ethical problems that cloning poses for individuals and society. These included, for instance, the potential stigma attached to being a cloned human being, kinship issues and the effect of cloning on sexual relations and procreation. In discussing cloning, participants also expressed concerns relating to eugenics, genetic engineering, uses of embryos for scientific experimentation and the regulation of scientists and scientific research. The initial post-Dolly report from The Wellcome Trust, thus, indicated a more widespread feeling towards cloning and biotechnology which was, at worst, antipathy and, at best, ambivalence (1998).

Within the Parliamentary debates, public anxieties around cloning developments were translated into an emerging 'anti-science climate' in the UK, by speakers from both sides such as Yvette Cooper[v], Baroness Warnock[vi] and Lord Alton[vii]. After the high profile media coverage of recent controversies, such as BSE/CJD and GM foods, science-public relations were perceived to be increasingly under strain. For those in favour of SCR, the emerging anti-science climate was identified in order to suggest that anxieties surrounding SCR could be attributed to the broader 'mood' (see, for example, Yvette Cooper, HC 17 Nov 2000: Col 1228-1229). Indeed, Baroness Warnock believed that fear and suspicion towards scientists and politicians has reached 'dangerous proportions', and subsequently went on to argue that:

> We are becoming a nation of cynics who cannot believe anything that they are told and who suspect the evidence and the motivation of the people who produce it. This is a situation that we ought to fear.

(HL, 22 Jan 2001: Col 43)

In pondering the relationship between opposition to the proposed amendment of the HFE Act and the perceived anti-science climate, Yvette Cooper argued that 'It would be a dreadful tragedy if the BSE crisis ... affected Members' judgement of the regulations' (HC, 17 Nov 2000: Col 1228-1229). Suggestions that arguments against SCR may be merely a reflection of a broader societal 'mood' served to discredit anti-research claims as ill-informed and fuelled by moral panic (Baroness Warnock, HL, 22 Jan 2001: Col 45).

That cloning techniques were being introduced at a time when science-society relations were under strain, led to the need for 'some serious PR damage limitation' (Sexton, 1999). Carl Feldbaum, head of the Biotechnology Industry Organisation in the US, warned that to mishandle the serious ethical issue of human cloning would threaten the survival of emerging biotech companies. He went on to say that 'no current issue has more potential to undermine public confidence in the whole field of genetic and biological research than human cloning' (Anon. *Financial Times*, 1998: Jan 11). Such sentiments echoed throughout the biotechnology industry in the UK due to the increasing mobilisation of anti-research lobbyists as reported in the media. This was evidenced by the lobbying of anti-research advocate, David Alton, who, in Parliament, voiced his opposition to the Government's role in facilitating cloning research through funding biotechnological organisations (HL, 3 Sept, 1998: Col WA65).

A comparison of the anti-research tactics of the current debates with those of the 1990 embryo research debates reveals that similar strategies were employed in both contexts. Anti-cloning and SCR campaigners such as David Alton and Ann Winterton mirrored their 1990 strategies in seizing upon the ethical problems raised by embryo research. In the context of the 1990 debates, anti-research lobbyists 'decided that assisted reproduction and abortion generated the same basic moral questions about the sanctity of life, about our obligations to the unborn and about the

nature of responsible parenthood' (Mulkay, 1997: 17). By the same logic, stem research was located in a lineage of issues which, according to speakers such as David Alton and Ann Winterton, firmly tied together concerns relating to abortion, assisted conception, embryo research and SCR. Similarly, during the HFE Act debates pro-research lobbyists such as the MRC were furious at what they regarded as attempts to sabotage much of its work in the area of embryo research by the pro-life alliances (Mulkay, 1997: 26).[viii] The considerable amount of time and research funds that had been put into developing the field of embryology, cellular development and genetic research were deemed to be under threat. Thus, in both the 1990 debates and the SCR debates, it was not only the future of the actual research that was deemed to be under threat by the growing anti-research lobby, but the integrity and future of the field of biotechnology. Whilst the pro-research lobby had been slow in mobilising itself during the 1990 debates, in the cloning debates scientists and related institutions were more actively engaged in a pro-research campaign from the outset.

Utilising tactics similar to those of the 1990 debates, both the MRC and Royal Society produced a fact sheet 'educating' the public and politicians outlining their position on SCR and cloning. Additionally, as Ann Winterton indicated in the House of Commons (17 Nov, 2000: Col 1200, 1205), representatives of science-based organisations, such as the MRC and BioIndustry Association, visited Westminster to speak to parliamentarians in an attempt to sway members who were yet to make up their minds on the issues. They also attempted to convert those who intended to vote against the amendment.

Winterton highlighted that following the publication of *The Donaldson Report*, there was a 'carefully co-ordinated propaganda campaign, with one group after another ... announcing their support for human cloning' (HC, 17 Nov 2000: Col 1200). In particular Winterton objected to the substitution of the term "cloning" with "cell nuclear replacement" by the 'fine-sounding bodies', such as those mentioned above, who supported the Donaldson reports

recommendations (HC, 17 Nov 2000: Col 1200). Winterton also pointed out that parliamentarians involved in the 1990 debates 'were subjected to an almost identical campaign [and that] the present campaign is little different' (HC, 17 Nov 2000: Col 1205). The similarities between the 1990 embryo debates and the stem cell debates in terms of strategies and rhetorical manoeuvrings, is indeed corroborated by Mulkay's analysis which illustrates the utilisation of fact sheets (1997: 39) and visits to MPs outlining the medical benefits of the proposed research (1997: 40-41) during the embryo debates of the 1980s.

The 1990 HFE Act debates were a rich source of rhetoric and tactics for the stem cell debates. Put simply, those against SCR seized upon the opportunity for redressing the embryo question and those in favour drew upon the successes of the 1990 debates by arguing that the pro-research lobby had already 'won'. Integral to the success of the pro-research campaign in gaining the legislative amendment, was the claim that SCR does not differ from IVF related research. Much of this argument was upheld by framing the stem cell discussions within the enclosure of debates about embryo research. That the use of the embryo for SCR would not breach the 14-day limit imposed in the 1990 Act, was an integral component of the pro-research position. In debating SCR according to the framework of the 1990 HEA Act, the pro-research lobby framed opposition to the proposed amendment as futile at best (afterall, the embryo debates had met their legal conclusion over a decade earlier), or insensitive at worst (for opposing therapies that could potentially cure as yet incurable illnesses and diseases). In doing so, public debates remained within well-trodden ground for the pro-research lobbyists, thus foreclosing debates surrounding wider social, legal and moral concerns regarding the development of cloning techniques.

Negotiating life: embryogenesis in the stem cell debate

In comparing analyses of the 1990 related debates with an analysis of the stem cell debates, one can determine similarities in terms of the dominance of the 'embryo question' (Franklin, 1999)

and the strategic politicking of the pro and anti-research lobbies. That questions regarding the status of the embryo remained central throughout the stem cell debates clearly illustrates the sociopolitical lineage and connections between IVF and cloning related issues. The legal and moral status of the embryo, as outlined during the 1990 debates and consequently enshrined in law, are repeatedly invoked in the context of these later debates about SCR. Thus, in the following section, the relevance of the 'embryo question' to stem cell cloning debates will be explored vis-à-vis its significance in the 1990 HFE Act.

Parliamentary SCR debates were couched in terms of a proposed amendment to the HFE Act and, therefore, it is perhaps unsurprising that there was a return to many of the issues discussed prior to 1990. What is surprising is the absence of discussions about the sociocultural implications of cloning technologies for kinship relations and health inequalities. Instead, the stem cell debates are nearly always couched within the terms of ethical considerations of embryo research, such as the point at which an embryo constitutes a human being, the ethico-legal status of embryos and the medical benefits versus the exploitation of embryos for research purposes. For those arguing against embryonic SCR, the debates provided an opportunity to restate their opposition to embryo research and related practices and to build further support. For those in favour of embryonic SCR, the focus on scientific issues relating to embryo experimentation, arguably, drew attention away from the more controversial issues relating to cloning through rhetorically separating scientific 'facts' from wider social and moral questions.

From the outset pro-research speakers asserted that SCR does not differ from embryo research already permitted under the 1990 HFE Act. The opening speech in the Commons by Yvette Cooper, the Parliamentary under-secretary of Sate for Health, indicated several rhetorical strategies that were to be employed by the pro-research lobby. She began by claiming that:

> Those who opposed the 1990 Act will doubtless oppose the regulations, too ... For those who support the 1990 Act and IVF treatments, there is a strong case for supporting the regulations, too.
> (HC, 17 Nov 2000: Col 1177).

The alignment of SCR with IVF related embryo research early on in the Parliamentary debate set the tone for further discussions. Along with many other speakers, Cooper began by outlining the existing HFEA regulations, adding that the proposed regulations would introduce a sixth category of embryo research: 'increasing understanding about human disease and disorders and their treatment' (Yvette Cooper, HC, 17 Nov 2000: 1178). The new category of research, it was argued, remained within the existing constraints of the HFEA, thus preventing the use of embryos over 14 days old:

> The proposals do not alter the special status of the embryo. Embryos of up to 14 days, the current cut-off point for research, are much smaller than the head of a pin, and the 14-day point is crucial because that is the earliest point at which the first parts of what will become the central nervous system can appear. We must recognise the importance and value of the embryo. The rules governing research on the human embryo must be tightly drawn, as, thanks to the 1990 Act, they already are.
> (Gareth R. Thomas, HC, 17 Nov 2000: Col 1197-1198)

That SCR would be subject to the HFEA's 14 day limit provided pro-research speakers with a powerful rhetorical tool for claiming that the proposed amendment would not challenge the 'special status of the embryo' (Warnock, 1985) as established in the HFE Act. The arbitrary and political underpinnings of the scientific explanation and justification for the establishment of a 14 day limit in the 1990 Act received no attention in the stem cell context, instead it was accepted as a 'biological fact'.[ix]

The point at which an embryo is ascribed the status of 'human being' in the HFE Act debates, was a notable point of contention. Many of those against embryo research, such as Lord Alton, argued that human life begins at the point of fertilisation. Indeed, to use embryos in scientific experiments was deemed to be 'cannibalistic' (Alton, HL, 22 Jan 2001: Col 28). All embryos, in this view, are ascribed the status of a human being and must be treated accordingly. Indeed, Ann Winterton, a vocal anti-research protagonist, stated that she found it 'frightening' that 'we have scientists who think of these [embryos] ... simply as a source to be exploited in obtaining cells and tissue' (HL, 17 Nov 2000: Col 1204)[x].

Anti-research arguments in the stem cell debates were significantly similar to those played out within the HFE Act debates. In charting the debates and processes leading up to the 1990 Act, Mulkay (1997) describes the strategies and rhetoric mobilised by the anti-research lobby. For Mulkay, the 'recommendations of the Warnock Committee in favour of embryo research gave the anti-abortion lobby the opportunity to revitalise its activities and, perhaps, to attract additional members by focussing attention on the new topic of the destruction of 'unborn children' in scientific laboratories' (Mulkay, 1997: 18). Previous debates surrounding the 1967 Abortion Act had already provided an established set of discourses that could be transposed to future debates relating to scientific and medical uses of embryos, including the harvesting of embryonic stem cells. Thus, in mobilising the rhetoric of human rights in the context of 'science out of control', the anti-research lobby were attempting to attract supporters as well as to revitalise more general issues relating to embryo research and the beginnings of life.

The response of those in favour of embryonic SCR was to agree that whilst an embryo should have some rights, these should not be the same as those of a baby or adult human being. Human rights should develop as the embryo develops. Such arguments often drew upon the rhetoric of

religion and moral philosophy. In combining scientific knowledge of embryo development and religious doctrine, speakers such as Robert Key and Dr Brand, respectively, argued that:

> I share the view of the former Archbishop of York, John Habgood, who has argued that the value that we attach to the lives of human beings--a value that is the root of all morality--increases as human life develops, and that we are therefore entitled, morally, to hold the life of a recently fertilised egg as less to be protected than that of a foetus at a later stage or a baby when it is born.
> (Robert Key, HC, 17 Nov 2000: Col 1215)

> I do not believe that foetal cells have the same status as a unique human being. If we are going to be theological about this, I do not think that the divine soul enters when an egg is fertilised ... there is a great difference between foetal material before 14 days--or indeed, a foetus of up to 22 weeks--and a born child.
> (Dr. Brand, HC, 17 Nov 2000: Col 1195)

One might expect the religious arguments to be mobilised by those opposing SCR, however, it was often pro-research speakers that referred to such sources. Rather than simply denunciating religious arguments against embryo research, as with the 1990 debates, pro-research speakers drew attention to the points of convergence of the two sides (see Mulkay, 1997: 102). They pointed to the special status of embryos beyond the 14-day period, and the protection that should be applied to foetuses and children.

Pro-research lobbyists, in anticipating theological arguments, posited the anti-research lobby as irrational, through parodying of the principle of ensoulment occurring at the point of fertilisation:

> Nature is profligate. We do not mourn for wasted sperm and eggs, alive though they are; nor for the three quarters of fertilised eggs that are lost before implant, half of which are genetically impaired. As the Bishop of Oxford has said, 'If every fertilised egg was indeed a soul... then, according to these figures, three quarters of heaven would be populated by souls that lived for less than a week'.
>
> (Robert Key, HC, 17 Nov 2000: Col 1215)

This science-based argument serves to normalise experimentation on embryos by claiming that scientific practice merely mirrors 'natural' processes and is therefore within the confines of acceptability. The 'natural' occurrence of miscarriage *in vivo*, is used to justify scientific uses of embryos. Baroness O'Neill argued that:

> In the normal course of events the cells of which this early stage of embryos is composed have an open future. They may become part of a human foetus and thence possibly, if all goes well, as a later stage of a human individual; or again, if much goes well, they become part of a human placenta; or they may— this is often the case— be shed. So I believe that we are not talking about a human individual or a human foetus.
>
> (HL, 22 Jan 2001: Col 67)

Such arguments, in mobilising science-based discourses of human development are instrumental in constructing the use of early embryos in research as 'natural' and unproblematic. The success of the pro-research lobby in the HFE Act debates was largely due to the 'transformation of participants' understanding of the experimental subject of embryo research' (Mulkay, 1997: 132). In using the term 'pre-embryo' to describe the pre-14 day old embryos, the meaning of the IVF-related research was shifted from one involving experimentation on defenceless human *beings*, to research on unformed biological *material*. Similarly, in the SCR debates, the success of the pro-research lobby can be attributed to the effective negation of the 'embryos are human beings'

argument. The anti-research lobby, thus, reiterated their basic moral (op)position to embryo research (which itself was taken from the anti-abortion movement (Mulkay, 1997: 132)), while the pro-research lobby maintained their established science-based rhetoric that embryos under 14-days old are merely biological material; a 'small collection of cells' (Joan Ruddock, HC, 17 Nov 2000: Col 1201). Again we see the framing of the debate according to scientific and medical knowledge, re-asserting the superiority of the scientific worldview (see Irwin and Wynne, 1996).

Both sides of the SCR debates have engaged with and utilised more recent scientific research which indicate that embryonic cells have the capacity to generate life. That is, embryonic stem cells contain the information for developing into any cell type, thus procuring the conceptual shift from the whole embryo to embryonic *cells*, as 'life itself' (Keller, 1995). This shift if evident in the following quotes from anti-research and pro-research speakers respectively:

> It is a most wonderful being, which has the capacity to initiate, sustain, control and direct its own development. Its cells provide every different kind of cell and tissue which make up the human body— skin, nerve, muscle, bone and other organs
> (Ann Winterton, HC, 17 Nov 2000: Col 1203)

> [embryonic stem cells] are pluripotent and capable of being precursors to a variety of human cell types and immortal.
> (Lord Patel, HL, 22 Jan 2001: Col 57)

Changes in the discourses of embryos must be located in the context of changes within science, or more specifically, genetics. Recent developments in genetic research have transformed biological discourse, as Keller has argued, 'The body of modern biology... has become just another part of an informational network, now machine, now message, always ready for exchange, each for the other' (Keller, 1995: 118; also see Franklin et al., 2000). This is pertinent

to the SCR debates, and in particular, the success of the pro-research lobby, in that this shift provides the basis for establishing embryonic SCR as benevolent. Today, the embryonic cell is increasingly replacing the whole embryo as a metonymy of life. Whereas in the HFE Act debates, the embryo was deemed to be the basic unit of life, the recent debates, whilst at once maintaining this notion, also challenged it in applying the same rhetoric to the cell.

In utilising a science-based discourse of embryonic cells rather than focussing upon social or ethical issues, the pro-research speakers went on to argue that the costs of *not* doing this research are the lives of people suffering from particular diseases. Anti-research speakers, on the other hand, used this to further consolidate their claims that embryos require protection:

> When the Minster tells the House of Commons that the pre-14-day-old embryo has the "power" to facilitate cures to mankind's misery, to me it simply underlines that, even at this early stage of development, we are not dealing with something that is inconsequential.
> (Lord Alton, HL, 22 Jan 2001: Col 29)

This constant return to the 'embryo question' throughout the debate was, in many ways, the safety net for the pro-research lobby. Comparisons to IVF-related experimentation enabled the side-stepping of broader issues – such as equal access to future health care provisions utilising stem cell techniques – and secured their success through the fall back position of the existing legislation within which the debates were contextualised:

> Some people object because we are creating embryos. That is already done and accepted.
> (Lord Taverne, HL, 22 Jan 2001: Col 64)

> We are not debating today the question of whether embryo research should be allowed. Parliament decided in 1990 under the Act that such research ... could be carried out.
> (Lord Walton, HL, 22 Jan 2001: Col 104-105)

Constructing a demand: Curing disease and disability

As part of the strategy for separating reproductive and therapeutic cloning, pro-research speakers repeatedly enlisted the support of groups with diseases and disabilities who are likely to be implicated in stem cell therapies. Groups such as people with Alzheimer's, Huntingdon's and Diabetes were constructed through emotive stories of illness and loss. Whilst there was not any consensus as to the means by which such groups could be helped, or even cured, both sides agreed upon their state of 'desperation'. The pro-research lobby focussed upon the potential of SCR to cure while the anti-research lobby argued that such claims were based upon false hopes and were, therefore, manipulative. In drawing upon an article in *Nature*, Mulkay (1997) shows how similar tactics were used during the 1990 debates. The article suggested that 'if a sufficiently strong link could be established between research on human embryos and increased control over genetic disability' then people's views about embryo research might be changed (Mulkay, 1997: 29). Hence, both cases focussed upon the benevolent applications for humans in aiming to transform SCR from a controversial practice into an accepted one.

The construction of a demand, or user-pull, is the focal concern of the next section where I will highlight the ways in which potential use-groups were recruited and caricatured during the Parliamentary debates. In comparing the SCR debates with the 1990 IVF and embryo research debates, I will reveal aspects of what Kirejczyk calls 'processes of entrenchment' (1995). Such processes involve struggles over definitions of the new practices according to existing linkages between 'technologies, problems, social interests, [and] arguments, socio-cultural values' (Kirejczyk, 1995: 3). Tracing the lineage of pro-research discourses about SCR to those associated with the 1990 debates reveals that processes of entrenchment of new technologies

follow similar patterns. That is, the creation of a demand for a new technology is an essential component for gaining acceptance and consent more broadly.

The recruitment of potential user-groups was pivotal to the pro-research lobby strategy and its eventual success. Parliamentarians articulated a demand for SCR by patient groups, in part, through references to letters received from individuals and organisations as well as emotive accounts of people with diseases such as Parkinson's. Speakers argued that they had a moral responsibility to these groups to allow SCR to go ahead:

> We have a duty to society and to the sufferers of degenerative diseases.
> (Joan Ruddock, HC, 17 Nov: Col 1211)

> Those who are ill and in pain cannot wait. We should not be dilatory.
> (Robert Key, HC, 17 Nov: Col 1213)

> Those who are suffering can only stand by and watch us decide.
> (Baroness Ashton, HL, 22 Jan 2001: Col 87)

In an attack on anti-research lobbyists, one speaker argued that 'some of the letters that I have had opposing the proposal are somewhat lacking in compassion for their friends and neighbours' (Robert Key, HC, 17 Nov: Col 1213). Thus, pro-research speakers drew upon the rhetoric of humanitarianism, arguing that to elevate the status of the embryo above that of people living with disease and disability, as the anti-research lobby was deemed to do, is to devalue existing life and therefore, unethical (Gareth R. Thomas, HC, 17 Nov 2000: Col 1198; Evan Harris, HC, 17 Nov 2000: Col 1217).

The construction of potential users according to narratives of hope and fear posits them as desperate. Gareth Thomas argued that without the development of SCR, many individuals along with their families and friends will continue to live in 'hell' (Gareth Thomas, HC, 17 Nov 2000: Col 1199); many others argued that these developments are the only chance for a cure for many people. In a similar way, during the 1990 HFE Act debates, men and women experiencing fertility problems or carrying genetic disorders were also discursively constructed as desperate and according to narratives of hope and fear. In both debates the pro-research lobby effectively articulated an account of scientific progress as alleviating pain and suffering. As Franklin has argued, 'it is significant that the depiction of scientific achievements in the form of new techniques are inserted within the narrative sequence framed by the hopes and desires of infertile couples' (1997: 94). That is, science and technology are positioned as a bridge at the point when 'life's 'natural' progression' is broken off by infertility or illness. Here, as with infertility treatment, the translation of the hopes and desires of groups with diseases and disabilities into 'desperateness' helps to naturalise stem cell cloning through embedding it within life's narrative sequence. This provides grounds for pro-research speakers to position themselves as responding in both an ethical and 'scientifically sound' manner:

> If research into human in vitro fertilisation and subsequent implantation of the embryo was not permitted, hundreds of thousands of couples today would not be parents. ... Today we have the same opportunity. It is hoped that we can allow but also regulate research that has the potential to help many others— those suffering from degenerative disease, diabetes, cardiac disease and those with injuries.
>
> (Lord Patel, HL, 22 Jan 2001: Col 57)

> This debate relates to the quality of life of sufferers from any dreadful diseases. It is not just a matter of quality of life; for some, we are talking about a question of life or death.
>
> (Lord Dubs, HL, 22 Jan 2001: Col 40)

> Millions of people— human beings— depend on us today not to take away something which is most important to them— that is, their hope for a more dignified happier and healthier future. That hope is becoming more realistic now... They want to be free from the pain and suffering brought about by the diseases which have attacked them.
> (Baroness Greengross, HL, 22 Jan 2001: Col 86)

As with other new technologies undergoing processes of 'entrenchment' (Kirejczyk, 1995), proponents of SCR must enable (or engender) the articulation of a demand for the new technology as part of attaining cultural and political acceptability. Similar patterns of entrenchment are being following in the case of the SCR debates to those followed by HFE Act and embryo research. There is a notable similarity between the creation of a demand during the IVF and the SCR debates. Mulkay (1997) notes how during the 1990 HFE Act debates the press reported how embryo research 'would lead to more control over pain, further relief from suffering, more frequent personal fulfilment and, hence, to greater joy and happiness' (1997: 70). He then goes on to say that, 'this message of hope was regularly conveyed and reinforced by means of highly personal narratives' (Mulkay, 1997: 70). Whilst Mulkay was referring to press reportage, there was also evidence of such tactics within Parliament. Using science-based arguments, pro-research speakers clearly adopted the rhetoric of hope to justify claims that IVF and related embryo research would engender 'a future in which countless people would have a realistic hope of achieving a better life with the help of the practitioners of embryo research' (Mulkay, 1997: 134).

The focus on potential cures for people was pivotal to the pro-research lobby for gaining support within parliament and also for gaining support from pressure groups and organisations out-with Westminster. Potential users were constructed as not only demanding but also *needing*

stem cell therapies; without them they would continue to suffer. The characterisation of people with diseases and disabilities as desperate was a powerful rhetorical tool for the pro-research lobby. The following quote demonstrates how emotive descriptions establish the notion of 'desperateness' of both those with diseases, along with their friends and families:

> [Parkinson's disease] means the end of an ability to work for someone who cannot rely on his or her body to carry out the most basic of functions–standing up straight and still, without jerking, or articulation of thoughts clearly to those he or she manages. Forced medical retirement comes next, and a gradual restriction of the social circle. Next is a declining ability to participate in conversations. There is a slow drop in the number of times the person can leave the house. There is an ever-increasing reliance and dependence on others— help with food, with getting into or out of bed, with going to the toilet, with going on holiday and for simply spreading ones wings.
>
> (Gareth R. Thomas, HC, 17 Nov 2000: Col 1199)

As Franklin argued in the context of infertility, 'the cause of 'desperateness', in other words, is represented as a failure to conform to social norms' (1997: 91). In the case of infertility, it is a failure to conform to conventional ideas of adult roles through the inability to 'found a family' (Franklin, 1997: 91). The 'desperateness' of individuals with disease and disabilities is a failure to conform to conventional adult roles in terms of bodily functions, notions of dependency and ability to engage in a range of 'normal' human activities.

Understanding the ideological processes involved in constructing a demand requires us to consider the meanings of ageing, disease and disability within contemporary society. We cannot detach the negotiation of entrenchment and processes of naturalisation of stem cell techniques from meanings of health and illness. Recent research in the sociology of disability has sought to deconstruct social and cultural meanings of disability, including the conflation of disability and

sickness, where the disabled body is conceived according to 'somatic and intellectual abnormality' (Paterson and Hughes, 2000; also see Turner 1995). In conflating disability and disease, the 'abnormal' body is constructed as 'an individual health problem and as an individual existential crisis which requires a charitable response' (Paterson and Hughes, 2000: 39). Disease and disability, like infertility, are stigmatised conditions, where once identified as such, 'all other identifying marks are washed away' (Pfeffer, 1987: 82). In sum, the understanding of potential user-groups according to dominant meanings of the elderly, disabled and sick reinforces and naturalises those ideas whilst simultaneously embedding stem cell techniques within established conventions of the treatment of illness.

Existing therapies and alternative research for developing treatments and cures were either ignored or mobilised in a strategic manner during the parliamentary debate. Crucial to the construction of potential user-groups as desperate was the construction of SCR as the only hope of producing therapies that would cure people. Examples of relatives who are ill or have already died were offered, providing emotive, personalised arguments intended to persuade both potential users and other parliamentarians that the 'solution provided by the new technology is a better one than the already existing options' (Kirejczyk, 1995: 2):

> I have a daughter for whom the ageing process came depressingly early, including the loss of her sight ... Research may be too late ... but for millions of mankind [sic] yet to come ... delay is simply no option.
> (Lord Rex, HL, 22 Jan 2001: Col 78-79)

> When my mother died, I felt helpless. Tonight, I am at least not helpless. I could not save my mum but tonight I can try to help to save someone else's.
> (Baroness Ashton, HL, 22 Jan 2001: Col 87)

Alternative research projects were only referred to in order to demonstrate that they were ineffectual as a cure or therapy. Therapies such as the injection of foetal brain cells to alleviate the symptoms of Huntingdon's and Parkinson's disease were discussed so as only to argue that such research is ethically problematic (see Lord Winston, HL, 22 Jan 2001: Col 100) and in practical terms, unfeasible (Lord Walton, HL, 22 Jan 2001: Col 105). Finally, the potential of SCR to provide cures rather than 'expensive or incomplete' pharmacological therapies or replacement surgery (Lord Rea, HL, 22 Jan 2001: Col 61), was a further argument mobilised by the pro-research lobby.

Claims made by pro-research speakers that stem cell therapies would empty nursing homes, thus relieving the 'burden on the health care system', framed their argument according to the responsibilities of a parliamentarian: to consider both economic and individual factors. Such arguments can also only intensify the 'somatisation of the self', where within a 'somatic society' matters of the body such as ageing, health and illness 'dominate the centre stage of political debate and political process' (Turner, 1995; 1996). Here, disease and disability are defined as individual and privatised, with matters of health and illness becoming an individual responsibility rather than a collective, social responsibility. Conversely, where we do see health and illness constructed as a public issue, as in the SCR debates, these are framed according to the terms of reference of the state and the 'medical science establishment' (Spallone, 1986: 549). That is, particular groups were defined according to processes of governance where people with various diseases where constructed as desperate and requiring intervention at the level of politics on behalf of science and medicine.

In the debates, as framed within the Parliamentary context, it has become increasingly difficult to raise broader questions about the appropriateness of cloning techniques. As Sexton has argued, 'If enough real-life stories of individual tragedies which could supposedly be averted through scientific progress can be played out one after the other ... it will seem churlish to ask

questions about public health systems, inequity, distribution, exploitation, racism, eugenics and corporate control, all of which will recede safely into the background' (1999). The parliamentary debates on medical applications of cloning techniques, under the official rubric of SCR, simultaneously constructed and elicited the support of potential user-groups and sympathetic groups. In representing the proposed research according to its medical potential and foregrounding stories of suffering to demonstrate the existence of a demand, more poignant questions were successfully nullified, and indeed, rendered irrelevant within the dominant discourse.

Repositioning infertility: From desperate to donors

The continuation of SCR for developing human therapies requires the co-operation of 'couples'[xi] undergoing fertility treatment to donate their spare embryos for research purposes. The views of people undergoing fertility treatment, however, have been conspicuously underrepresented either in or outside of Parliament. Whilst there has been plenty of debate over the embryos in question, little attention has been paid to the sources of embryos for SCR: women undergoing IVF. Where we do see references to those people expected to donate their embryos, the discourses mobilised are revealing of social and cultural processes involving ideas of health and illness in the context of reproduction.

Explicit references to the sources of embryos were always made by pro-research speakers in the Parliamentary debates. Couples undergoing fertility treatment were rhetorically recruited as allies during the debate as 'public spirited people' (Lord Walton, HL, 22 Jan 2001: Col 107) wanting to donate their spare embryos for benevolent purposes rather than have them 'destroyed'. Donating embryos for SCR, it was argued, resulted in embryos playing 'a useful role instead of vanishing into thin air' (Lord Rea, HL, 22 Jan 2001: Col 59). By this connection, those who donate their embryos would be 'contributing to the well-being of current and future generations' (Lord Rea, HL, 22 Jan 2001: Col 59).

This emotive rhetoric, as described above, is in keeping with dominant discourses of reproduction in science and medicine that couples undergoing IVF come to be familiar with. A central feature of reproductive discourses is one that entails ideas, or indeed, judgements about what constitutes a normal or an abnormal body. For those undergoing fertility treatment, issues around normality and abnormality are particularly pertinent due to their embodied negotiation of 'deficient', infertile bodies, and IVF procedures such as pre-implantation genetic diagnosis.[xii] Ettorre refers to this as a 'disablist discourse' (2000). The management of bodies during fertility treatment by experts is, in part, organised according to broader social models of disability, which characterises bodies according to 'rigid definitions of health and illness' (Ettorre, 2000: 404). Given that those required to donate embryos will already be confronted with issues concerning disability through reproductive practices such as embryo selection, amniocentesis, and pre-natal screening, they are likely to have already developed an 'antipathy to what is considered to be undesirable physical, sensory or mentally-related difference or 'abnormality' in their bodies' (Ettorre, 2000: 412-413). The call to arms by pro-research speakers for 'couples' to donate spare embryos to 'advance the common good' (Joan Ruddock, HC, 17 Nov 2000: Col 1210) is dependent upon already established complex social and cultural constructions of health and illness. Therefore, there is less rhetorical work to be done by the pro-research lobby to encourage couples to donate their spare embryos.

In the context of embryo donation for medical research, couples are subject to discourses of responsibility. These discourses of responsibility extend beyond responsibilities to a potential child, but also include responsibilities to the science and medical profession with which they are engaged. Joan Ruddock, in her speech, recruited the support of donors in arguing that:

> More than most, they have an acute sense of what life is. They also have lengthy and close contact with medical science and an appreciation of the efforts of those who work in the service of human health and well-being.
>
> (HC, 17 Nov 2000: Col 1210)

Here the discourse of gift exchange is mobilised, where in return for medical science helping couples to conceive a child, they have a responsibility to donate their spare embryos for SCR. There is a presumption that in participating in fertility treatment, 'couples' are in agreement with the dominant scientific model of embryos and life. This greatly simplifies the relationship between individuals undergoing fertility treatment, their embryos and the clinicians, which are complex and often contradictory. Whilst on the one hand fertility clinics trade on the construction of embryos as potential sources of life, and actively encourage the engagement of 'couples' in embryo selection and transfer processes (Goslinga-Roy, 2000). On the other hand, clinicians also 'destroy' embryos as part of the IVF process, requiring the discursive separation of 'good' embryos from 'bad' ones. This is achieved through employing developmental criteria as recorded in the lab 'exempting certain embryos from the moral and legal standards that apply to embryos as potential sources of life in the lab' (Cussins, 1996: 587).

Adult versus embryonic stem cells

Debates regarding the use of embryonic versus adult stem cells[xiii] became a key controversy within the Parliamentary context. Concerns were articulated according to the scientific, ethical and political issues surrounding their respective advantages and disadvantages. Permeating the SCR debates were discourses of progress where SCR was intimately associated with the development of science, the economy and the human race. Whilst the pro and anti-research lobbies envisaged different methods for developing stem cell therapies, in terms of the sources of cells, both sides talked uncritically of the role of SCR in furthering progress. As already indicated above, neither side considered alternative therapies, but instead focussed upon the

relative costs and benefits of using embryos or adult tissue for SCR purposes. That SCR is characterised by scientific uncertainty and controversy, often meant that this particular issue was, ultimately, fought on the grounds of the 'embryo question'. In the following section I will focus upon some of the underlying assumptions that permeated questions over sources of stem cells and how the pro and anti-research lobbies responded to this controversy.

Speakers advocating the use of embryos as a source of stem cells framed their arguments according to seven main, albeit overlapping, elements. Firstly, as already discussed earlier, the use of embryos for SCR was not seen to challenge the 1990 HFE Act. That embryos would not be used beyond the established 14-day limit and the research aims are essentially therapeutic, gave credence to claims that there are no 'great new ethical issue[s] here' (Gareth R. Thomas, HC, 17 Nov 2000: Col 1197). Secondly, delaying the legislative amendment to allow embryonic SCR, it was argued, would slow down the research process and the expediency for developing stem cell therapies. Arguments for the swift development of stem cell therapies were made in conjunction with four other points: the co-development of adult and embryonic SCR, long-term research would not involve using embryos, the need for cures, and the role of SCR and biotechnology in the UK economy. Each of these points will be addressed in the following discussion.

Debates over the sources of stem cells were largely framed according to scientific and technical issues. The anti-research lobby argued that adult stem cells are 'easier to manage' *in vivo* and have already been demonstrated to have health care benefits for many conditions (Ann Winterton, HC, 17 Nov 2000: Col 1204, 1205). As in the 1990 embryo research debates (see Kirejczyk 1999: 93), the parliamentary opponents of embryonic SCR switched from a rhetoric of fear to one of hope when discussing alternatives to embryonic stem cells. Speakers such as Ann Winterton, again using scientific rhetoric and evidence, argued that there is insufficient scientific evidence to support claims that embryonic SCR will 'kick start' therapeutic breakthroughs (HC,

19 Dec 2000: Col 243). Conversely, in drawing upon published scientific papers, adult stem cell sources such as umbilical cords and bone marrow were cited as having already provided some therapeutic benefits (Bill Tynan, HC, 19 Dec 2000: Col 251). Furthermore, it was argued, the 'deep divisions within the medical scientific community constitutes a strong reason for deferring making a definitive, irreversible decision today' (Baroness Cox, HL, 22 Jan 2001: Col 55).

In agreeing with the potential of adult stem cell sources, pro-research speakers, however, argued that in order to ensure the development of therapies scientists should pursue both embryonic and adult SCR:

> There is not an either/or choice between adult stem cells and embryonic stem cells ... The proposals do not suggest that research into adult stem cells should be stopped. ... However, we cannot stop research in one area in the hope that another area may yield results.
>
> (Dr Evan Harris, HC, 17 Nov 2000: Col 1220)

> It is thought that [embryonic stem cells] will increase the speed at which we obtain knowledge, [and] increase the range of diseases that we can treat and trigger the first breakthrough
>
> (Yvette Cooper, HC, 17 Nov 2000: Col 1228)

Again, arguments for the co-development of both embryonic and adult SCR were framed according to scientific and technical issues, the 'desperation' of potential user-groups and 'speed'. Scientific controversies concerning the two sources of stem cells were mobilised to justify the need to develop both techniques: if scientists are unsure as to which stem cell source will provide the breakthrough, then both avenues should be pursued. Discussions between scientists and MPs were recalled as scientific evidence within the debates. In acknowledging the

importance of adult SCR, pro-embryonic SCR speakers argued that many scientists believe that adult stem cells do not have the 'plasticity' of embryonic stem cells and, therefore, 'their use and applications are much more limited' (Lord Dubs, HL, 22 Jan 2001: Col 40).

Pro-research speakers lauded the significance of embryo research in developing therapies. Claims that embryonic stem cells would speed up the research process (Gareth R. Thomas, HC, 17 Nov 2000: Col 1198) and 'trigger the first breakthrough' (Yvette Cooper, HC, 17 Nov 2000: 1228) in understanding processes of cell differentiation, were tempered with the inevitable redundancy of embryonic SCR. At the point of application adult stem cells rather than embryos, it was argued, would be used for human therapies:

> The beauty of the procedures we are discussing today is that they have the potential to make themselves redundant in the not to distant future. When the scientists have learnt enough from the cells from an embryo source, it is not beyond the bounds of possibility that they may in future be able to use cells from the adult to be treated, which will have no likelihood of rejection.
> (Baroness Walmsley, HL, 22 Jan 2001: 102)

> The likelihood, in future, of being able to use adult stem cells or even adult cells for therapeutic purposes requires, initially, research on embryonic stem cells, cells that are pluripotent and capable of being precursors to a variety of human cell types and immortal.
> (Lord Patel, HL, 22 Jan 2001: Col 57)

Thus positing that a decision to permit embryonic SCR is a short to mid-term practice and legislative change to permit this will simply bring forth therapeutic advances. In treating stem cell therapies as a homogeneous area, where a breakthrough in one disease such as Parkinson's

signals a breakthrough writ large, is misleading. The fragmented nature of scientific research according to specialist areas, which themselves have developed according to differing historical trajectories, suggests that a unified breakthrough for all the diseases and disorders listed by scientists is a false supposition. Whilst serving as a placatory mechanism, arguments that there will be one particular point at which embryonic research is no longer needed is, therefore, overly simplistic and monolithic in its model of science.

As indicated in the introduction, the outcome of the SCR debates was deemed to be indicative of the state of science, or more specifically biotechnology, within the UK in terms of public support and science-public relations. Speakers in favour of embryonic SCR often contextualised SCR according to the role of biotechnology in the UK economy. In amending the HFE Act to incorporate SCR the UK economy would, in turn, be bolstered. This was further supported by the British Prime Minister at the European Biosciences Conference in November 2000, aiming to bring together the views of the biotechnology industry and parliament, crucially, during the week when SCR debates took place in the House of Commons. Blair warned against a growing 'anti-science' culture within Britain, announcing his support of SCR and the 'revolutionary potential of biotechnology' (cited in Clark, 2000; BBC, Friday 17 Nov 2000). In debating the economic value of SCR developments and the potential to develop cures for a wide range of diseases, demonstrates the successful bringing together of the interests of the biotechnology industry and government.

Claims focussing upon the economic benefits of SCR were not only made with reference to alleviating the 'burden' on the health care system through cures, but also through elevating UK scientists working in biotechnology to world leaders in their field. Indecision, it was argued, would lead to the UK losing its lead in the field of genetics (Baroness Kennedy, HL, 22 Jan 2001: Col 47; Baroness Cox, HL, 22 Jan 2001: Col 55; Lord Patel, HL, 22 Jan 2001: Col 58), with the additional problem of leading scientists leaving the UK to continue their research

abroad (Lord Hunt, HL, 22 Jan 2001: Col 94). It is perhaps not insignificant that two days before the first parliamentary debate *The Times* ran a story with the headline 'Britain's biotech talent may flee 'hostile' climate', claiming that UK public attitudes to science were the worst in the world, and that research was suffering (Henderson, 15 Nov 2000). Additionally, within parliament, it was stressed by Baroness Kennedy, that the UK would 'be faced with pressure to import expensive stem cell therapies, possibly those developed in an ethically dubious and less well-regulated manner' (HL, 22 Jan 2001: Col 47). Thus, the framing of pro-amendment arguments according to the role of SCR, and biotechnology more generally, within the UK economy, also contextualised the proposed amendment within a the broader context of a biotechnology 'race' akin to the space race.[xiv]

Conclusions

Within this paper I have attempted to show how dominant discourses in the SCR debates, as (re)produced in Parliament, provide interesting analytical nodes from which we can observe the jostling over meanings and rhetoric by those actors and agencies involved. It is not insignificant that debates regarding the future of SCR and, by default, the development of cloning techniques have hinged upon an amendment to the 1990 HFE Act. The introduction of stem cell technologies occurred through the amendment to legislation that regulates a relatively normalised practice. This suggests that Mulkay was indeed correct in his supposition that:

> there will ... be no mad rush down the slippery slope. Rather, in Britain, there will be a cautious, gradual, almost imperceptible movement into a future in which nothing will be certain except that, in the long run, the practices, expectations, values and morality associated with human reproduction will have been transformed.
>
> (1997: 154).

This paper illustrates how the rhetorical construction of SCR in the Parliamentary debates slips seamlessly into existing ideas, values and practices, particularly those relating to health, illness and scientific progress. Invocations of the 1990 HFE Act have served to frame stem cell developments on safe ground by focussing upon embryo research. Broader implications of SCR and cloning related developments were largely muted, such as the financial cost of health care access to any therapies developed and implications upon sociocultural notions of life, death and nature. Also, whilst lip-service was paid to controversies surrounding SCR, ultimately, the grounds on which the debate took place were achieved through what Gieryn calls 'boundary-work' (1995).

Whilst this paper has focussed upon the rhetorical manoeuvrings relating to the SCR debates within Parliament, the next important step in exploring the public debates surrounding cloning related developments should address the omissions, the gaps and the silences. Such an endeavour could begin by analysing the issues as defined according to the various public groups, for whom SCR and related cloning developments may have an impact upon their lives. In moving away from debates framed according to 'operational categories of government' (Irwin, 2001: 9) we can begin to explore the multiple constructions of cloning as they relate to peoples' everyday experiences and social location. As a technology in the early stages of scientific development and social entrenchment, jostling over meanings continue to be mooted. Therefore, as far as cloning is concerned, all hands are yet to be played.

Bibliography

Anon. (1998) Time to Act on Cloning. **Financial Times**, Jan 11 http://globalarchive.ft.com/globalarchive/articles.html?print=true&id=980111002691# [29/05/01]

Anon. (2000) UK developing anti-science culture. **BBC News Online**, 17 Nov http://news.bbc.co.uk/hi/english/sci/tech/newsid_1028000/1028911.stm [20/11/00]

British Medical Association (1999) BMA backs limited therapeutic cloning with strict safeguards, Thursday 24 June 1999. http://web.bma.org.uk/pressrel.nsf/a4a6effeb2d171b8802568590051feb8/49332ddf33b6da7b802568f500543109?OpenDocument [15/05/01]

Clark, Andrew (2000) Blair Talks up Biotechs. **The Guardian**, 18 Nov http://www.guardianunlimited.co.uk/Archive/Archive/0,4273,4092801,00.html [20/11/00]

Crowe, Christine (1990) Whose Mind Over Whose Matter? Women, In Vitro Fertilisation and The Development of Scientific Knowledge. In McNeil, Maureen et al. (eds.) (1990) **The New Reproductive Technologies**. Basingstoke: Macmillan

Cussins, Charis (1996) Ontological Choreography: Agency through Objectification in Infertility Clinics. **Social Studies of Science**, Vol. 26, pp. 575-610

Department of Health (June 2000) **Stem Cell Research: Medical Progress with Responsibility**. London: DoH http://www.doh.gov.uk/cegc

Ettorre, Elizabeth (2000) Reproductive Genetics, Gender and the Body: 'Please Doctor, may I have a Normal Baby?' **Sociology**, Vol. 34, No. 3, pp. 403-420

Franklin, Sarah (1997) **Embodied Progress: A Cultural Account of Assisted Conception**. London: Routledge

Franklin, Sarah (1999) Making Representations: The Parliamentary Debate on the Human Fertilisation and Embryology Act. In Edwards, J. et al. (eds.) (1999) **Technologies of Procreation: Kinship in the Age of Assisted Conception**. (2nd Ed.) London: Routledge.

Franklin, Sarah, Lury, Celia & Stacey, Jackie (eds.) (2000) **Global Nature, Global Culture**. London: Sage

Franklin, Sarah (2001) Sheepwatching. **Anthropology Today**, Vol. 17, No. 3 (June 2001)

Franklin, Sarah, Anthony Rutherford & Peter Braunde (2001) Project Outline. In, **Definitions of Genetic Knowledge and Pre-Implantation Genetic Diagnosis: An Ethnographic Study**. ESRC funded project: Innovative Health Technologies Initiative. http://www.comp.lancs.ac.uk/sociology/IHT/Mainpage.htm

Gieryn, Thomas F., (1995) Boundaries of Science. In Jasanoff, Sheila et al., (eds.) (1995) **Handbook of Science and Technology Studies**. London: Sage

Gilbert, Nigel G. and Mulkay, Michael (1984) **Opening Pandora's Box: A Sociological Analysis of Scientists' Discourse**. Cambridge: Cambridge University Press

Goslinga-Roy, Gillian M. (2000) Body Boundaries, Fiction of the Female Self: An Ethnographic Perspective on Power, Feminism, and the Reproductive Technologies. **Feminist Studies**, Vol. 26, No. 1, (Spring 2000)

Hansard, House of Commons debates, 17 Nov 2000. http://www.parliament.the-stationary-office.co.uk/pa/cm199900/cmhansrd/cm001117/debindx-x.htm

Hansard, House of Commons debates, 19 Dec 2000. http://www.parliament.the-stationery-office.co.uk/pa/cm200001/cmhansrd/vo001219/debtext/01219-07.htm# 01219-07_head0

Hansard, House of Lords debates, 3 Sept 1998. http://www.parliament.the-stationery-office.co.uk/pa/ld199697/ldhansrd/pdvn/lds98/text/80903w16.htm

Hansard, House of Lords debates, 22 Jan 2001. http://www.parliament.the-stationary-office.co.uk/pa/ld199900/ldhansrd/pdrn/lds01/text/10122w01.htm

Henderson, Mark (2000) Britain's Biotech Talent May Flee 'Hostile' Climate. **The Times**, Nov 15 http://www.thetimes.co.uk/article/0,,2-35902,00.html [17/04/01]

Human Fertilisation and Embryology Code of Practice, Fifth Edition, April 2001. http://www.hfea.gov.uk/code2001/cop2001/pdf

Human Genetics Advisory Commission and Human Fertilisation and Embryology Authority (January 1998) **Cloning Issues in Reproduction, Science and Medicine**. http://www.dti.gov.uk/hgac/papers/paperc1.htm

Irwin, Alan and Wynne, Brian (1996) Introduction. In Irwin, Alan and Wynne, Brian (eds.) **Misunderstanding Science? The Public Reconstruction of Science and Technology**. Cambridge: Cambridge University Press

Irwin, Alan (2001) Constructing the Scientific Citizen: Science and Democracy in the Biosciences. **Public Understanding of Science**. Vol 10, pp 1-18

Keller, Evelyn Fox (1995) **Refiguring Life: Metaphors of Twentieth-Century Biology**. New York: Columbia University Press

Kirejczyk, Marta (1993) Shifting the Burden onto Women: The Gender Character of *In Vitro* Fertilisation. **Science as Culture**, Vol. 3, Pt. 4, No. 17, pp. 507-521

Kirejczyk, Marta (1995) **Gender and the Social Entrenchment of IVF in the Netherlands**. Paper for the International Workshop on the Mutual Shaping of Gender and Technology, Enschede, October 6-8, 1995

Kirejczyk, Marta (1999) Parliamentary Cultures and Human Embryos: The Dutch and British Debates Compared. **Social Studies of Science**, Vol. 29, No. 6 (December 1999), pp. 889-912

Meek, James (2001) The Brain Gain. **The Guardian**, Tuesday 14 August 2001

Mulkay, Michael (1993) Rhetorics of Hope and Fear in the Great Embryo Debate. **Social Studies of Science**. Vol. 23, No. 4, pp. 721-742

Mulkay, Michael (1994) The Triumph of the Pre-Embryo: Interpretations of the Human Embryo in Parliamentary Debate over Embryo Research. **Social Studies of Science**. Vol. 24, pp. 611-639

Mulkay, Michael (1997) **The Embryo Research Debate: Science and the Politics of Reproduction.** Cambridge: Cambridge University Press

Nettleton, Sarah (1995) **The Sociology of Health and Illness.** Cambridge: Polity Press

Paterson, Kevin & Hughes, Bill (2000) Disabled Bodies. In Hancock, Philip *et al.* (2000) **The Body, Culture and Society: An Introduction.** Buckingham: Open University Press

Pfeffer, Naomi (1987) Artificial Insemination, In-vitro Fertilization and the Stigma of Infertility. In Stanworth, Michelle (1987) **Reproductive Technologies: Gender, Motherhood and Medicine.** Cambridge: Polity Press

Sexton, Sarah (1999) If Cloning is the Answer, What was the Question?: Power and Decision-Making in the Geneticisation of Health. In **The Corner House**, Briefing 16, 1999. http://cornerhouse.icaap.org/briefings/16.html [06/04/01]

Spallone, Patricia (1986) The Warnock Report: The Politics of Reproductive Technology. **Women's Studies International Forum**, Vol. 9, No. 5, pp. 543-550

Spallone, Patricia (1989) **Beyond Conception: The New Politics of Reproduction.** London: MacMillan Education

Turner, Bryan S. (1995) Aging and Identity: Some Reflections on the Somatization of the Self. In Featherstone, Mike & Wernick, Andrew (eds.) (1995) **Images of Aging: Cultural Representations of Later Life.** London: Routledge

Turner, Bryan S. (1996) **The Body and Society** (2nd Edition). London: Sage

Van Dyck, José (1995) *Manufacturing Babies and Public Consent: Debating the New Reproductive Technologies*. Basingstoke: MacMillan

Warnock, Mary (1985) **A Question of Life: The Warnock Report on Human Fertilization and Embryology.** Oxford: Blackwell

Wellcome Trust (1998) **Public Perspectives on Human Cloning: A Social Research Study.** London: The Wellcome Trust

---

[i] I would like to thank Sarah Cunningham-Burley, Wendy Faulkner, Ki-heung Kim, Gill Haddow and the *NGS* reviewers for their helpful comments on earlier drafts of this article. Their advice and recommendations were greatly appreciated.

[ii] Existing regulations permitted embryo research that related directly to reproductive medicine: contraception, miscarriage, infertility and the detection of abnormalities prior to implantation. The three added categories were as follows: i) to increase knowledge about the development of embryos ii) to increase knowledge about serious disease iii) to enable any such knowledge to be applied in developing treatments for serious disease (HFEA Code of Practice, Fifth edition, April 2001: 53)

[iii] De-differentiation was the initial term used by Ian Wilmut to describe the technique used for cloning Dolly the sheep. This is where cells that have become specialised, such as skin or nerve cells, are re-programmed in order to become any cell type. However, Wilmut has since questioned the accuracy of this term, in suggesting that cells never fully differentiate to begin with, hence retaining their capacity to be re-programmed (see Franklin, 2001: 7).

[iv] I have used the 'pro' and 'anti' research labels as shorthand for the purposes of this paper. Whilst the debates were not entirely polarised around two positions – with individual

speakers inhabiting complex and often contradictory positions – the debates were often structured around Parliamentary conventions: a vote of either for or against.

[v] Yvette Cooper was the Parliamentary Under-Secretary of State for Health and an advocate for stem cell research and the proposed amendment to the 1990 HFE Act.

[vi] Baroness Warnock, a pro-research advocate and moral philosopher who chaired a committee of inquiry in 1982 to 'examine the social, ethical and legal implications of recent, and potential developments in the field of assisted [human] reproduction' (Warnock, cited in Mulkay, 1997: 3). This recommendations from this committee formed the basis of the 1990 HFE Act.

[vii] As an active pro-life campaigner, David Alton was and continues to be a vocal critic of embryo research, stem cell research and cloning related developments. During the stem cell debates Lord Alton had proposed alternative legislation which would put embryonic stem cell research on hold until after a select committee had considered the implications of the research.

[viii] In particular, the MRC were reacting to the success of Enoch Powell's Unborn Children (Protection) Bill in 1985. The scientific community had been shocked by the size of the vote against embryo research which saw 238 votes in favour and only 66 against. This was further compounded by an article in Nature that attempted to show how the 'enactment of Powell's Bill would prevent specific advances' (Mulkay, 1997: 27). The positive response to the Powell Bill by politicians gave the pro-research lobby the impetus to form an organised network during the 1990 embryo research debates. Up until this point the pro-research lobby had been uncoordinated compared to the energetic lobbying by anti-abortion and anti-embryo research lobbyists. The Powell Bill was eventually defeated.

[ix] See Mulkay (1994) for an excellent discussion of the coining of the term 'pre-embryo' during the 1990 debates. Also, see Pat Spallone (1989) for a brief discussion of the establishment of the 14 day limit (pp. 50- 55).

[x] Within this part of the debate Winterton explicitly outlined her belief that embryos are not simply human cells, but are 'definitely human'.

[xi] In using the term 'couple' I acknowledge that fertility treatment, whilst rhetorically treating the 'couple', actually involves medical interventions on the female body to a much greater extent than the male body. 'Except for the selection and laboratory preparation of the sperm for fertilisation, the whole procedure is performed on women' (Kirejczyk, 1993: 518; also see Crowe, 1990) regardless of whether infertility is due to female or male fertility problems. Having said this, I am assuming the decision-making processes for embryo donation involves a complex negotiation between the man and woman trying to conceive, and health care professionals attached to the clinic.

[xii] Pre-implantation genetic diagnosis (PGD) is a technique used for screening embryos for genetic diseases/disorders before they are implanted into the woman's uterus. At present this technique is in its early stages of development and is only used for those at high risk (1 in 4) of passing on terminal disease to their offspring (Franklin et al., 2001). The potential for widespread use of PGD for preventing the transmission of hereditary disorders raises pertinent questions about constructions of health and illness, normal and abnormal bodies.

[xiii] Embryonic stem cells are derived from embryos under fourteen days old. Stem cells are extracted from the embryo and then cultivated in the lab to produce stem cell lines. An adult stem cell is derived from tissue such as bone marrow or blood from a range of sources including umbilical cords and people of all ages. Stem cell research, regardless of the source, aims to understand the process of cell development and differentiation: the process by which cells develop into particular cell types such as brain tissue, and to develop methods to direct cells to develop into particular cell types.

[xiv] The narrative of the global biotechnology 'race' has been further solidified by the recent race to map the Human Genome. 'Competition' is pitted in terms of publicly versus privately funded research - Britain versus the US respectively.

APPENDIX II

Stem Cell Research and Cloning: An Account of 'The Science'

What Are Stem Cells?

Stem cells are cells in the body that do not have any specialised physiological properties: for instance, they are not red blood cells that carry oxygen around the body. They are described by scientists as 'unspecialised'.

Stem cells are believed to be able to do two things:

1) They have the capacity for what is called 'self-renewal'. This is where they divide and replicate themselves.
2) Secondly, under the correct culturing conditions, they can give rise to specialised cell types, such as nerve or blood cells.

Adult Versus Embryonic Stem Cells

It is thought that there are a number of sources of stem cells within the human body, but scientists are not in agreement as to a) where they are and b) which stem cells are the most useful for research purposes. Research on human stem cells is usually described as either 'adult' or 'embryonic' stem cell research, which refers to the sources of material from which stem cells are derived:

i) *Adult Stem Cells*

There are a number of sources of adult stem cells within the human body, including the bone marrow, liver and spleen. Other sources that are also described as 'adult' stem cells are umbilical cord blood, placenta blood and material taken from aborted foetuses.

ii) *Embryonic Stem Cells*

The second and most controversial source of stem cells is human embryos. This involves isolating stem cells from embryos during early stages of development – at around 5-6 days old – and growing them in cultures.

In both adult and embryonic stem cell research, scientists are trying to understand how stem cells 'decide' between simply replicating themselves or becoming specialised cell types. This involves identifying the genes and proteins involved in cell development and regeneration with the aim of learning how to control and manipulate cells and tissues. This is the process known as *'differentiation'* whereby a cell (either embryonic or adult) becomes a specialised cell type such as nerve, muscle or neurons.

One of the main scientific disputes within the field of SCR relates to the 'plasticity' of stem cell sources. 'Plasticity' refers to the number and range of cell types that can be 'made' from different stem cell sources. For instance, scientists working on embryonic SCR (eSCR) are sceptical as to how 'plastic' adult stem cells are, arguing that they can only give rise to a limit range of cell types. Adult stem cells are, therefore, referred to as *multipotent* stem cells – having the potential to give rise to a limited range of cells and tissues. Conversely, embryonic stem cells are referred to as *pluripotent* stem cells – able to give rise to any specialised cell type in the adult human body. However, this dispute remains unsettled as scientists working with adult stem cells continue to show that such cells have a greater degree of plasticity than is currently credited.

Stem Cell Therapies: The Uses of Controlling Cell Differentiation

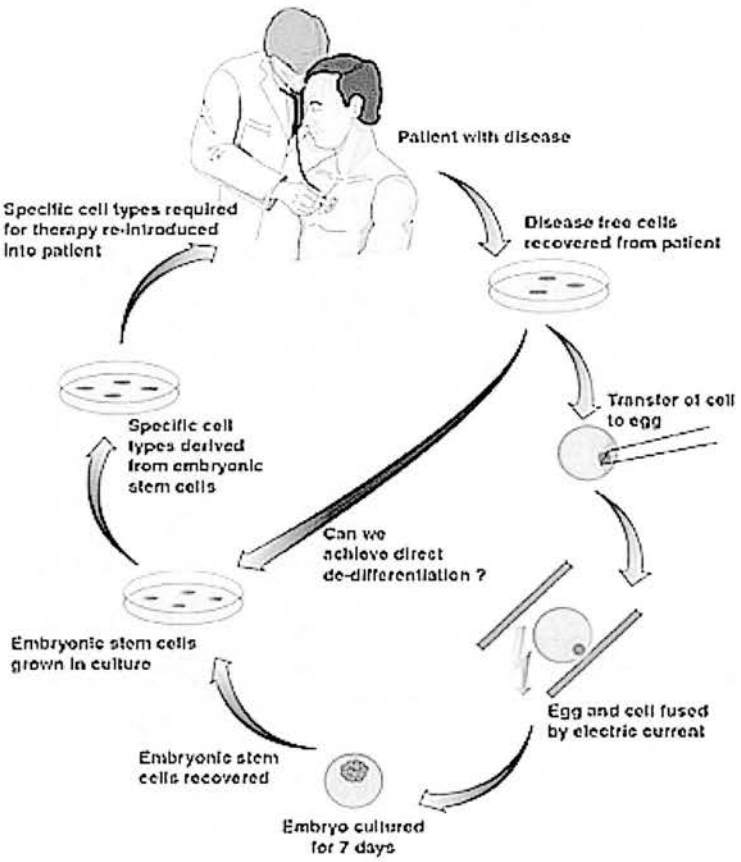
One of the main aims of SCR is to direct stem cells in the laboratory to produce specialised cell types wanted for transplantation. For instance, to produce pancreatic cells for people with Diabetes, brain cells for people with Huntington's, Parkinson's or Alzheimer's disease and nerve cells for people with spinal cord injuries. Other uses of SCR are to help understand how a complex organism develops from a fertilised egg, what controls normal cell development, and, therefore, what contributes to abnormal cell development in cases such as cancer. A further potential use of SCR is to understand how and why cells 'age' or degenerate, and how to control or reverse the ageing process.

Stem Cell Research → Therapeutic Cloning

For the purposes of cell transplants, just to produce relevant cells types does not solve the problem of histocompatibility – that is, the transplanted cells would not match the immune system of the recipient. If stem cells are developed from adult or embryonic stem cells taken from somebody other than the patient requiring the transplant, the patient would need immunosuppressant drugs, which bring their own complications. There are two potential

solutions to this problem. The first is to use adult cells taken from the patient requiring the transplant, derive the relevant cell type from this, then transplant them back into the patient. Because the tissue was taken from the patient, the stem cells would match their immune system and would not require immunosuppressant drugs regimes. A second option is to combine SCR with the technique used to clone Dolly the sheep called cell nuclear transfer replacement (CNR). Because of the use of the cloning technique, this has earned the name 'therapeutic cloning'.

The process involved in 'therapeutic cloning' is depicted in the diagram below:



Starting from the top of the diagram, a cell would be taken from the patient requiring the cell transplant. At this stage, scientists would also require a donated egg from a woman.[1] Then the nucleus of the cell from the egg is removed and the nucleus of the cell from the patient is

[1] The processes of 'harvesting' oocytes (to use the technical name) requires women to take large doses of hormones to stimulate their ovaries. Here, rather than only one or two eggs maturing (as would happen during the normal menstrual cycle), the hope is that a number of eggs mature at once – this is called hyperovulation. Then the eggs are retrieved through inserting a long needle through the woman's abdomen, into the ovaries and then extracting the eggs. There are a number of health risks involved in such procedures including infection and resultant infertility.

inserted (as represented by this icon of an egg with a needle in it). An electric current is then applied to the egg containing the genetic information of the patient. This electric current simulates the sperm entering the egg, causing it to start dividing as though it had been fertilised. What I have described so far is the nuclear transfer technique used to create Dolly. If at this point the embryo was successfully implanted into a woman's womb, then this would be the process of reproductive cloning. In the case of 'therapeutic cloning', the embryo is allowed to develop in vitro (in a cell culture) for around 5-6 days, after which scientists could then extract stem cells, grow them in a culture and direct them into the cell type needed by the patient. The biological material produced would match the recipients immune system and they would not require immunosuppressant drugs.

The above diagram also depicts stem cell therapies using adult tissue, as indicated in the arrow in the middle with the corresponding question "can we achieve direct de-differentiation?" This process would not require human embryos and would still produce cell types that are compatible with the recipients' immune system.

It is important to note that the above account of stem cells, SCR, 'therapeutic' and 'reproductive' cloning are, like all areas of scientific research, provisional and partial. This description is heavily influenced by the version of SCR and cloning that has gained legitimacy within the policymaking context of the Parliamentary debates and ensuing policy documents in the UK which, in turn, has been shaped by eSCR advocates and excluded advocates for adult SCR. Also, as is argued throughout this thesis, such accounts of SCR excludes the views of a range of non-scientists for whom SCR and cloning developments may have an impact.

APPENDIX III

Coding Tree

1 = **Experts/Expertise**

- Views of politicians
- Views of Scientists
- Views of Publics

2 = **Public debate**

- Lineage of issues
- Entrenchment of reproductive cloning
- Role of media
- Clarity/effective communication
- Entrenchment of therapeutic cloning

3 = **Risk**

- Slippery slope
- Wrong hands/mad scientists
- Health care access/genetic underclass
- Trust/behind closed doors
- Risk to health
- Eugenics

4 = **Driving research?**

- Cloning as lifestyle choice
- Motivation for reproductive cloning
- Demand/motivation for therapeutic cloning
    - 'Therapeutic' cloning as alternative to existing medical therapies
- Prestige/fame/fortune for scientists
- Scientific/human progress
- Demand for reproductive cloning
    - Reproductive cloning as alternative to existing fertility treatment

5 = **Science today**

Role in UK economy

SCR and cloning as "space race"/international competition

Patenting

Science-out-of-control/fear

Uncertainty

Practical/technical/scientific constraints

6 = **Imagining cloning: Use of cultural resources**

Meaning of word "cloning"

References to specific films/fiction

7 = **Distinctions between 'reproductive' and 'therapeutic' cloning**

8 = **Meaning of embryos**

Embryonic versus adult stem cells

9 = **Human Uniqueness: Genes vs. Environment**

Being a Clone

10 = **Regulation and control**

Consent

11 = **Embodied biography/lived experience**

12 = **Sex/Gender assumptions**

13 = **Natural/Unnatural**

14 = **Ambivalence**

15 = **Kinship**